ANNALES
UNIVERSITATIS MARIAE CURIE-SKŁODOWSKA
LUBLIN – POLONIA
VOL. LX, N 2, 124 SECTIO D 2005

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# *Suffering as a call for the integrative cancer care practice*

In his classic paper *The Nature of Suffering and the Goals of Medicine* of 1982 Cassell challenged the separation of illness into physical and psychological states. He asserted „suffering is experienced by persons, not merely by bodies" and suggested that understanding the place of the person in human illness requires a rejection of the historical dualism of mind and body. In Cassell's view, suffering occurs when the individual perceives impending destruction and is in a state of severe distress associated with events that threaten the intactness of an individual (4). Cassel's classic work has served as a guiding force in challenging the medical profession to examine its goals and to recognize the moral mandate to attend not only to physical illness but also to the suffering that accompanies it. When discussing the reductionistic model of medicine – it seems that nurses have been less inclined to consider a mind and body separation because they have recognized and embraced their professional domain to encompass the whole person. The mission, vision and standards of oncology nursing are embedded in recognition of cancer as a life-threatening illness with dimensions of physical, psychological, social, and spiritual well-being (8).

Suffering is often discussed in professional oncology literature as a component of quality of life (QOL). A diagnosis of cancer and treatment has a profound impact and a great influence on QOL. Patients with cancer have described seeing their image in a mirror and reflecting on the physical devastation of disease and treatment. The illness is often perceived as insult to the spirit. This recognition of decreased QOL leads the patient to become aware of the devastation and an altered life that has diminished meaning. This decreased meaning leads to suffering. Relief of suffering is, thus, seen as an essential QOL intervention, particularly when the patient has advanced disease and the goals of care shift to providing the comfort rather than cure. Suffering is present across many chronic illnesses, but cancer has unique qualities as a life-threatening illness in relation to suffering. Upon first hearing of a cancer diagnosis, most patients and the public associate the diagnosis with two other concepts: pain and death. Many cancer survivors who experienced long-term remission discussed the loss of their future, as they believe that the physical effects of the illness and treatment, despite a good prognosis, mean that they will not live a long life. As an aspect of QOL suffering is included in the domain of spiritual well-being, at the same time it is a component that transcends the other domains of physical, psychological, and social well-being (Ferrell 1996). While these QOL studies have included varying populations across the cancer trajectory, suffering is evident as a component in each. Suffering begins not at the transition from chronic illness to terminal illness but rather at the moment of diagnosis. This model is particularly relevant to patients with advanced cancer who are experiencing pain (5).

The specific events related to cancer are recognized as to cause the suffering. One of the hallmarks of the cancer experience is that of loss. Cancer patients experience phenomenal sacrifice, beginning with the physical losses associated with cancer treatment, such as loss of the breast or hair. Prolonged and advances illness involves losses of relationships, responsibilities, and autonomy and the threat of

loss of life itself. Many patients have described their experiences as a gradual unwinding – one layer of their lives is removed at a time. Patients have described their loss of a sense of health once this devastating diagnosis was made.

Another classic contributor to the field of suffering – Victor Frankl is a founder of a psychotherapy modality known as logotherapy. Logotherapy attempted to help individuals to find meaning in their experiences. As a concentration camp prisoner, Frankl applied his observations and experiences to individuals who survive life-threatening illnesses. He observed that prisoners like himself, who had a will to live or a purpose to sustain, were able to find meaning in their suffering and, thus, to survive. In applying these moral and existentional lessons to therapeutic relationships, Frankl believed that the clinician's role is to assist the person in finding the meaning in suffering (5).

Oncology professionals recognize that nursing has a unique role and contribution to cancer care, and recognize that nursing has a unique contribution to the relief of suffering. Copp, a pioneer in applying the concept of suffering to the nursing profession, defined suffering as a state of anguish in one who bears pain, injury, or loss. Her classic work challenges nurses to assess and intervene in suffering. Oncology nurses are intimately involved in the cancer journey, traversing the phases of cancer survivorship. Nurses are present with the patients and the family from the beginning to the very end of care. They are present during the shock and suffering associated with a new diagnosis, through the trials of aggressive treatment, the uncertainty and apprehension of remission, the devastation of recurrence, and the suffering associated with facing death from advanced disease. Nurses are instrumental in moving patients from the anguish of suffering to an experience of deriving meaning from suffering (2, 5, 14).

## SUFFERING AND CANCER PAIN

Cancer-related pain is common. Patients with cancer reported that the prevalence of pain requiring analgesics varies, but has been estimated between 20% and 50% in patients with early-stage disease and 55% and 95% in patients with advanced cancer (2). The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage (12)". Pain is reaction to stress, which affects the functioning of the whole human organism. Pain as a complex phenomenon was divided in a variety of ways. Initially, only psychic components were distinguished, later pain was treated as sensory impression (2, 6). At present the following components can be differentiated in the structure of pain: • Somatic component (sensory impression) • Psychic component (cognitive and emotional elements) • Mixed component, psycho-somatic (behavioral element).

## EXPERIENCE OF CANCER PAIN

Cancer pain has a negative meaning in psychosocial and spiritual aspects of suffering of a man approaching the end of his/her life. Irreversibly, constantly reappearing body lesions caused by neoplastic disease, disability and complications of neoplasm treatment cause pain and other concomitant symptoms (dysponea, vomiting, nausea, asthenia, insomnia). These feelings are accompanied by anxiety, depression and aggression (3). Frequently the pain psychic syndrome is developed, which is characterized by mood depression, hypersensitivity, limitation of the range of interests and despondency about life. Spiritual pain leads to the quest for the sense of life, to the struggle between despair and belief in God, people and eternal life (5). Pain and uncertainty about the future are accompanied by insomnia or dyssomnia, which increase suffering and cause further deterioration of the general condition of a patient. The sensation of pain considerably intensifies when a man is left alone in the dark to face his

thoughts and fears. These are the words of a female patient suffering from urinary bladder cancer: "The nights are horrible, almost unbearable. At night my bed becomes entirely different place than during the day. Most of all I dread the nights, as I am left all on my own with my nagging pain, surrounded by other patients suffering like me.

Unrelieved pain is incapacitating and precludes a satisfying quality of life. Often it interferes with physical functioning and social interaction, and is strongly associated with the psychological distress. Pain, which becomes persistent, interferes with the sick person's ability to eat, sleep, think, and interact with family, friends, significant others as well as with the medical staff. The relationship between pain and psychological well-being is complex and reciprocal. Disturbance in mood and beliefs about the meaning of pain in relation to illness can affect the perceived pain intensity, at the same time – the presence of pain is a major determinant of function and mood. The presence of pain may have a negative influence on normal processes of coping and adjustment as well as augment a sense of vulnerability. It may also contribute to a preoccupation with the potential for catastrophic outcomes. The relationship between pain and psychological distress among people who suffered from cancer has been demonstrated in a range of tumor types. That particular relationship has a dangerous potential, as uncontrolled pain is a major risk factor in cancer-related suicide and the most of psychiatric symptoms have commonly been observed to disappear with adequate pain relief (5).

## CARING FOR CANCER PATIENT SUFFERING FROM PAIN

Pain plays an important role in patients' responses to illness and overall sense of well-being. Pain control may be problematic for a variety of reason, including the difficulties of objective assessment of this subjective symptom. Although physicians order analgesics, the drugs are often ordered as needed, leaving nurses to decide on the dose and the schedule. This decision is usually dependent on nurses' perceptions of patients' pain. In order to provide appropriate pain management, accurate pain assessment in necessary. Research suggests that improving nurses' pain assessment will improve patients' pain management (13). Pain is a common symptom faced by hospitalized patients. Several national and international institutions have taken positions on pain management. The American Pain Society developed Quality Assurance Standards for Relief of Acute Pain and Cancer Pain in Oncology Nursing Practice (12). For many healthcare providers managing chronic cancer pain can be a complex and overwhelming experience specially if opioid tolerance is involved (3). Misconceptions about chronic pain management and unfounded concerns of tolerance development have identified as potential impediments to the provision of adequate pain management, which is consistent with the reported undereducation regarding pain management issues among many physicians and nurses. In a survey of all Eastern Cooperative Oncology Group physicians, 52% reported quality of their medical education regarding management of cancer pain to be poor, and 22% reported concern of developing tolerance to potent opioids too rapidly as a primary reason for prescribing less potent analgesia. Recent emphasis on pain management education for nurses and medical students may be helping to improve these numbers. Nurses who work within the oncology settings, home health, and hospice are frequently involved in identifying and assessing changes in pain status, patient and family counselling/education, and ongoing re-evaluation and management of pain control (3).

## ASSESSMENT AND TREATMENT OF CANCER PAIN

Cancer pain has a negative effect on the functioning of other systems and organs of the organism, and it causes hypertonia, respiration and circulation disorders, constipation, loss of appetite, and other

problems. Appropriate understanding of these conditions enables complex therapy and an integrative medical care for a hospitalized patient whose principal purpose is not only providing a selective analgesic management, but fulfilling psychological, social and spiritual needs as well. Assessment is an ongoing and dynamic process that includes evaluation of presenting problems, elucidation of pain syndromes and pathophysiology, and formulation of a comprehensive plan for continuing care. The objectives of cancer pain assessment include: accurate characterization of pain, including the pain syndrome and inferred pathophysiology, and the evaluation of the impact of pain and the role it plays in the overall suffering of the patient. This assessment is predicated on the establishment of a trusting relationship with the patient, in which the clinician emphasizes the relief of pain and suffering as central to the goal of therapy and encourages open communication about symptoms (3, 5).

The information obtained from the subjective and objective data provides the basis for a provisional pain diagnosis, an understanding of the disease status, and the identification of other concurrent concerns. This provisional diagnosis includes inferences about the pathophysiology of pain and an assessment of the pain syndrome. It is a common problem of patients with cancer to experience the pain at more than one site. The distinction between focal, multifocal and generalized pain may be important in the selection of therapy, such as nerve blocks, radiotherapy or surgical approaches. Pain caused by cancer may be acute or chronic. A careful review of the past medical history and the chronological issues of the cancer pain is important to place the pain complaint in the proper context. The history related to pain must elucidate the relevant pain characteristics, as well as the responses of the patient to previous disease curing and analgesic therapies (5).

Neoplastic disease afflicts mainly elderly people; this is why it is important to pay attention to their isolation. Even the best method of killing pain may prove ineffective when physical suffering is increased by isolation. "Assessing pain in cognitively impaired older adults with cancer presents a challenge to healthcare providers. As the age and number of older adults with cancer and cognitive impairments increase, so does the need for appropriate methods and instruments to adequately assess pain in this population. Oncology nurses report pain control to be one of the more challenging aspects of caring for patients with cancer." A practical approach to cancer pain assessment incorporates a stepwise approach that begins with data collection and ends with a clinically relevant formulation. A careful review of past medical history and the chronology of cancer is important to place the pain complaint in context. The pain-related history must elucidate the relevant pain characteristics, as well as the responses of the patient to previous disease-modifying and analgesic therapies. The presence of multiple pain problems is common, and if more than one is reported, each must be assessed independently. The validated pain assessment instruments can provide a format for communication between the patient and health care professionals and can serve also as a monitoring tool to assess the adequacy of therapy provided. The consequences of pain should be also assessed by clinician. Those includes: impairment in activities of daily living; psychological, familial, and professional dysfunction; disturbed sleep, appetite, and vitality; and financial concerns. The patient's psychological status, including current level of anxiety or depression, suicidal ideation, and the perceived meaning of the pain, are similarly relevant. The presence of dysfunctional attitudes, such as pessimism, idiosyncratic interpretation of pain, self-blame, and perceived loss of personal control, can usually be detected through careful questioning. It is an important part of a good clinical practice to assess the patient-family interaction and to note both the kind and the frequency of pain behaviors and the way in which the family reacts (5, 11, 15).

The method recommended by WHO for patients with cancer disease is the administration of analgesic medication at a particular dose (established individually for each patient), and at equal intervals, usually every 4 hours (this is related to analgesic medication action time). It should be noted that

cancer pain requires regular administration of analgesic medicines at even intervals (e.g. every 4 hours). When medicine administration exceeds the pain, a patient does not have to constantly ask for help. He, or she, remains fully conscious, is able to think about something else and forget about the pain (1, 2, 6). Analgesic medicines should be used to prevent the very appearance of pain, and not to alleviate pains that have already begun. This requires of a nurse to perform "careful analysis of the situation, paying attention to details, excessive nursing care, and listening to patients in order to know what they feel, and in order that they know that we are interested in that". Failure to recognize the importance of interindividual drug metabolism, interactions, and the variability in response to common medications used to provide palliative interventions can lead to overdosing or the undertreatment of symptoms that interfere with patients' perceived quality of life. It is important to ensure a patient that we have analgesic medicines at our disposal which can relieve pain, that we are able to control it, and that a patient will be free from pain, and able to perform any form of physical activity which is appropriate to their fitness and agility (1). The clinician should assess the consequences of pain, including impairment in activities of daily living; psychological, familial, and professional dysfunction, disturbed sleep, appetite, vitality and financial concerns. The patient's psychological status, including current level of anxiety or depression, suicidal ideation, and the perceived meaning of pain is equally important. Most patients with cancer pain have multiple other symptoms. The clinician must evaluate the severity and distress caused by each of these symptoms. Symptom checklists and quality of life measures may contribute to this comprehensive evaluation as well as play a key role to the QOL improvement. "Integrating palliative interventions throughout the clinical course of patients' cancer treatment experience promotes quality of life" (6, 10).

## ROLE OF ONCOLOGY NURSE

A nurse plays an important role in pharmacotherapy of cancer pain, since administering medicines she observes their efficacy; therefore, she should have rudimentary knowledge of the action mechanism of administered medicines, their side effects and treatment efficacy. Pain treatment in oncology patients requires of a nurse to know the action time and strength of a medicine, its toxicity, accumulation, and possible addiction. Medicine administration should be a part of the comprehensive process of patient care. This process should be aimed to enable a patient to remain conscious, to prevent any addiction to analgesic medicine, i.e. the necessity of taking medicine for any other purposes than pain treatment. The nurse, as a member of the therapeutic team, spends a considerable amount of time with the patient while administering medication, performing various nursing and therapeutic procedures, which creates favorable conditions to learn about the patient's problems. Participating in the management of common symptoms (e.g.: pain, dyspnea, fatigue, depression) requires skilled nursing assessment and the use of knowledgeable interventions, such as medication administration, through a coordinated and continuous pattern initiated throughout the cancer experience from the time of the diagnosis until death (9, 10). Therefore, palliative care interventions should be considered throughout patient's disease trajectory and not reserved for the imminently dying or performed within a time-defined framework, such as at the end-of-life (6).

"The goal of palliative drug therapy is to control, relieve, or eliminate symptoms. This can be accomplished by assessing and evaluating the interindividual responses to specific medications, keeping medication use to a minimum, and appreciating that every patient will react differently to specific medications administration likely will result in ineffective symptom management for patients receiving palliative care" (4, 10).

The constant increase of neoplasm incidence results in the growing number of hospitalized cancer patients. This necessitates the education and training of personnel for providing nursing care for hospitalized patients. Such care should consist in the methods of analgesic treatment and the treatment of other side effects caused by chemo- or radiotherapy, tending patients, ensuring their emotional security and spiritual comfort. The humanistic knowledge of the nurse providing medical care to patients with incurable diseases must undergo profound transformation in the direction of human sympathy and understanding of patients, in order to bring the human nature of the patient into the focus of medical attention; the patient should feel that he is the center of a caring attention. These conclusions should become a challenge to medical staff involved in the care of oncology patients exposed to extreme pain, to increase their qualifications and improve the quality of medical care.

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SUMMARY

Recent surveys indicate that pain is experienced by 30–60% of cancer patients during active therapy and more than two thirds of those with advanced disease. This has been acknowledged in a series of the studies, which identified pain prevalence among patients with newly diagnosed cancer. The number is growing among patients receiving active anticancer therapy to reach about I' among patients with far advanced disease. The high prevalence of acute and chronic pain among cancer patients, and the profound psychological and physical burdens caused by this symptom, oblige all treating clinicians to be skilled in pain management. Within the integrative oncology care – it as an ethical imperative to relief of pain in cancer patients and nurses and doctors do realize the professional obligations to maximize their knowledge, skills, and diligence needed to attend to this task. The undertreatment of cancer pain has many causes, among the most important of which is inadequate assessment, which could be seen the same time as the iatrogenic outcome and should be assigned as to the priorities in improvement of the professional practice.

Cierpienie jako sfera wyznaczająca zintegrowany charakter opieki w chorobie nowotworowej

Choroba nowotworowa jest z reguły źródłem ogromnego cierpienia psychicznego. Szczególnym wyzwaniem profesjonalnym jest opieka sprawowana w sytuacji dalekiego jej zaawansowania, łączącego się z cierpieniami, zarówno fizycznymi, jak i duchowymi. W trakcie choroby nowotworowej występuje wiele objawów ze strony poszczególnych układów, co prowadzi do problemów w obrębie biologicznego funkcjonowania człowieka. Z powodu bólu cierpi około 50-80% chorych na nowotwory. Ból, jaki odczuwa chory, obejmuje nie tylko jego ciało, ale dotyczy całej sfery psychospołeczno-duchowej. Celem opieki nad człowiekiem w stadium cierpienia jest działanie na rzecz maksymalizacji komfortu i jakości życia chorego i jego rodziny, poprzez adekwatne rozpoznawanie oraz systematyczne, ciągłe i skuteczne rozwiązywanie problemów przede wszystkim natury fizycznej, ale także psychicznej, społecznej i duchowej. Na stan psychospołeczny, w jakim znajduje się chory i jego rodzina, ogromny wpływ mają problemy istniejące w sferze biologicznego funkcjonowania człowieka. Ogromną rolę odgrywa wsparcie udzielane członkom rodziny i osobom najbliższym. W leczeniu bólu somatycznego, wywołanego zaistnieniem choroby ale też i terapią nowotworu, należy stosować leki przeciwbólowe według zaleceń WHO, a personel medyczny powinien dołożyć wszelkich starań, aby osiągnąć skuteczny poziom analgezji, to znaczy aby chory nie odczuwał bólu lub jeśli nie jest to możliwe – aby odczuwał go w stopniu możliwym do zniesienia. Opieka onkologiczna powinna mieć zintegrowany charakter. Powinno to być działanie zespołowe o charakterze interdyscyplinarnym, dobrze zorganizowane, planowe i systematyczne, tak aby z jednej strony skutecznie osiągnąć najlepszą z możliwych jakość życia osoby chorej oraz osiągnąć satysfakcję zawodową. Wszystkie osoby zaangażowane w działania powinny rozumieć naturę cierpienia i starać się otoczyć pacjenta i jego rodzinę opieką i troską na miarę doniosłości potrzeb i wagi przeżyć. Cierpienie jest sytuacją trudną, wymagającą i graniczną, gdzie nie brakuje okazji po temu, aby zarówno człowiek chory, jak i opiekun zdali egzamin z własnego człowieczeństwa. W opiece onkologicznej transcendencja obecna jest na co dzień: ważne jest nie tylko samo znalezienie, ale i poszukiwanie sensu i wartości uniwersalnych.