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*The professional information, education and counselling
as the prerequisites for quality cancer care*

Supportive care in cancer patients is a concept that has evolved in the last two decades. The struggle against cancer as a life-threatening disease was primarily understood in terms of the destruction of cancer cells, the stopping of tumor growth, and the increase in survival time. The progress of medical science in the twentieth century allowed many patients to understand that even cancer could be cured, or at least controlled, over years. Thus, success has inspired hope and improved quantity and quality of life for many patients. Once it became possible to increase survival time, the quality of life debate became more relevant. Death was no longer seen as the greatest and sole enemy of quality of life (6). But cancer is still a very emotive word that frightens and shocks people, their relatives and friends. The range of conflicting emotions experienced during diagnosis and treatment may be difficult for health professionals to respond to, especially if their work is not solely with people affected by cancer. Psychosocial, emotional support and information is vital but not always easy to offer. Fear of saying too much and causing distress gets in the way of finding out what people really need. Each individual's emotional and cultural requirements are unique and making assumptions about a person's need for information and support is counter-productive.

Health care professionals may be concerned as to what the patient and their relatives have been told and what they know and understand about the illness. Relatives attempting to shield the ill-person from the bad news and vice versa may create a web of half-truths and untruths. In addition, nurses' and doctors' own experience of cancer will influence, perhaps subconsciously, the way they view the disease and those that suffer from it.

NEED FOR PSYCHOSOCIAL SUPPORT

Despite dramatic progress in cancer treatment in recent years, it continues to be one of the most feared diseases. Polish society still associates cancer with death, suffering, or disfigurement. Some people with cancer could fear being ostracized, treated differently, or misunderstood. As a result, they may experience an additional psychological burden of keeping their illness a secret from the others. Cancer causes social role changes, affects the entire family system and may upset its balance. The consequence may be increased tension and stress for the ill person and other members of the family: Family members' responses to the situation caused by the presence of the illness can have a significant impact on the patient's adaptation process.

To most effectively assist the patient, caring interventions should address the problems and needs of the entire family (1,2,4).

NEED FOR EMOTIONAL AND SPIRITUAL SUPPORT

It is now widely acknowledged that the discovery by a person that he/she has cancer leads to a profound and all-pervading sense of disorientation. This disturbing feeling often persists throughout the illness whether the patient recovers or dies. It calls into question many of the ideas and values on which he has based his life and strikes at the roots of the feeling of "permanence", which all people have about themselves, disturbing the patient's sense of identity. It changes his status from that of how he/she used to think, of a healthy person, to a patient and moreover to a cancer patient with all the images of sickness and suffering which these words evoke. This situation always leaves the person stunned for a while, and calls forth a wide range of intense and contradictory feelings in which fear predominates: fear of death, of pain, becoming dependent, of being alone, abandoned, losing the loving ones and their love. Those fears, which are not externalized, are a source of intense anguish.

WHY TO OFFER SUPPORT

The distress and guilt resulting from being a cancer patient may cause depression and anger, or it may cause the patient to turn in on himself, regressing to a state of dependence on others. These factors lead to a change in his relations with other people, including his closest family and friends, and have a great impact on the relations with medical and nursing staff. Effective coping strategies and good communication are essential for quality care. In the course of the disease, patients need to feel that their family and caregivers (nurses, doctors) understand them and will respond to their needs properly. Nurses can encourage families to cultivate several communication skills that support the patient. Active listening is a skill that asks the caregiver to "be there" for the patient physically and emotionally. Open communication is another important skill for those who care for cancer patients.

COPING

Patients' and families' responses to the diagnosis of cancer will usually resemble their previous way of coping during the past crises. "Everyone copes differently; variations in coping ability are often a function of the individual's religious and cultural background and early life experiences. Some people even describe the overall cancer experience in positive terms, because the process of coping reveals inner strengths and establishes, in a dramatic way, the priorities of life" (5). The situation of having a life-threatening disease makes many patients feel that they have lost control of their lives. Restoration of this control or sense of mastery over one's environment can give patients coping strength and is therefore a major goal of providing the psychosocial support.

HEALTH PROFESSIONALS AS A SUPPORT NETWORK

Caring for those who suffer from cancer can be both rewarding and stressful for the health professional: a nurse and doctor and their families. "However, caring for patients and families who are suffering physically, emotionally and spiritually is professional life can be enriched by opportunities to use knowledge and skills and to maintain significant relationship with patients emotionally draining. Maintaining a balanced life and developing supportive networks in and

out of the workplace are important strategies for all health care professionals" (5). For many reasons, it is the right solution to offer a support group for cancer patients, their families and the caregivers.

SUPPORT GROUPS

Health care providers and the general public are increasingly recognizing and accepting support groups for patients with cancer and their families as an integral part of cancer care (3, 11,12). These groups will become more valuable in filling "the service gap" created by cost containment and extended cancer survival (15). Benefits of support groups include an opportunity to share experiences and information, they prevent isolation, foster hope, discover and teach effective coping skills and strategies, and validate perceptions and feelings (1,12,13). Some other benefits described by Bloom (2) consist in maintaining a social identity and social affiliation and providing tangible environmental as well as emotional and spiritual support. The positive effects of support groups in one or more domains of quality of life were proved by researchers in more than dozen controlled cancer-care studies (3).

According to Leavitt, Lamb and Voss (10), the two major inclusive concept categories of supportive mechanism emerged while studying the data: finding a safe haven and maintaining the morale. Finding a safe haven: Validation in shared experiences and new possibilities, Patience for the time to tell and explain; a special understanding, expressing worst fears to face painful realities, silence for reflection, respect, and caring, caregivers sharing troubles and ways of coping, modelling open communication.

Maintaining the morale: • Reference comparison: New normality; measuring, rehearsing, • Reducing expectations: Tempering hope, • Giving and receiving cycles: Changing places, • Realistic reassurance: Interpretation and correction, • Hope: Reprieve and cure, finding sources, facing the challenge, affirmation of life, • Sharing coping strategies: Empowering, living normally; managing deficits, • Humor: Catharsis, pulling together, sharing the moment.

An important function of support groups may be to provide a non-threatening forum for releasing anger that patients and their families cannot express directly toward the medical staff. Several mechanisms for the increased survival times were operand in different support groups. "These include (a) relaxation and relief in a safe haven where feelings, even worst fear, were expressed and perception validated, where coping strategies were shared, where others were patient when words could not be recalled, and where caregivers could speak with one another and know they were not alone, and (b) social support, evident in the reduced sense of isolation, reference comparison, and shared experiences and circumstances" (10).

The support group successfully combines self-help with professional care paradigms. Health care economics mandate the development of cost-effective health care services. Group modalities for health assessment and health care delivery; even for complex problems, currently being instituted for management of chronic disease (8,10). Support groups facilitated by expert nurses may provide a cost-effective alternative to office visits for patients and caregivers, or even prevent short-term hospitalization due to minor health problems. Furthermore, the group process can assist with vicarious support and family communication. Exposure to models of family relationship and practical care issues may reduce caregiver fatigue and burnout (7).

The role and specific contribution of the nurse facilitators was threefold: clinical knowledge of disease (cancer and its treatment) and caring/nursing problems caused in psychosocial, emotional and spiritual dimensions of life; knowledge of coping and adjustment to trauma and loss and expertise in promoting positive coping through exploration, acknowledgement, highlighting of important topics, "permission giving", encouragement and demonstration of therapeutic communication; knowledge of therapeutic group process (e.g., allowing silences, responding to emotional tone, providing structure and limits, maintaining a group atmosphere of safety; confidentiality and respect).

The truth basis for a support group running or providing the effective psychosocial and emotional support is open communication between the patients and doctors, nurses, and the family members. The need for good communication begins before the diagnosis is made and includes the way the diagnosis is told (7,8). If the patient is not cured the need extends to support during the illness and treatment, through palliative care to bereavement counseling for the careers. "On the evidence available to them the Select Committee agreed that for many if not most cancer patients the quality of communication between the patients and health staff, doctor and nurses, is unacceptably poor. This is true both for the circumstances in which the diagnosis and prognosis are told as well as for the way in which they are told. Too often hospitals are places of silence with the patients not daring to ask the questions which matter to them, so protecting themselves and those around them from their pain and fear. A wall of silence is erected on both sides, which is very difficult to break down even with the best of intentions. If nothing breaks the silence it becomes a vicious circle disturbing personal relationship, rendering communication impossible and isolating the patient. For centuries the training of doctors has concentrated on the physical aspects of care at the expense of the patient's psycho-logical needs. Often the members of the medical profession meet challenge of a person with cancer by means of pure technology, which though necessary and essential to progress may become a substitute for talking to the patient and his family. Some doctors and nurses are conscious of their own problems in this area. In a recent survey general practitioners and nurses rated their own lack of communication skills and their inability to provide emotional support. These are areas in which many clinicians practicing today did not receive adequate training in their medical and nursing schools. They are topics infrequently addressed during the continuing education programs although guidelines exists (5). The essential element of an open communication is the proper way of telling the bad news.

WHEN, WHERE AND HOW SHOULD THE DIAGNOSIS BE TOLD? BREAKING BAD NEWS

"Bad news" can be defined as any information that drastically alters a patients' view of their future for worse. Breaking bad news is an important skill for all doctors, because medical care often involves imparting bad news, whether about illness ('Your weakness will not improve') or treatment ('The chemotherapy will have side-effects') or prognosis ('This disease will shorten your life'). Many other professional also need to know how to break bad news, since they frequently share the task with the doctor" (9). The author proposes a ten-step approach to breaking bad news, which emphasizes that it is a process that resembles holding a negotiation more than giving a sermon.

10 steps to breaking bad news: 1. Preparation. 2. What does the patient know? 3. Is more information wanted? 4. Give a warning shot. 5. Allow denial. 6. Explain (if requested). 7. Listen to concerns. 8. Encourage ventilation of feelings. 9. Summary-and-plan. 10. Offer availability

Kaye (9) points out that the patient has a right, but not a duty; to hear bad news, and that is why the negotiation is needed. According to the author, most patients want two things: 1. A certain amount of information (the right amount). 2. The opportunity to talk and think about their situation: a therapeutic dialogue (9). "Tilley found that patients acknowledged nurses as sources of certain information. They preferred to receive information from the nurses concerning the event of illness and about what to expect in the future. However, patients preferred to receive medically oriented information from doctors (2,5,14). These findings suggest that nurses and doctors can and must have different emphases in information giving" (6).

There are roles which should be respected by the policy makers as well by the individual staff-members: 1. Never inform a patient about the cancer diagnosis before the final proving report is available (biopsy or cytology). 2. Making an office appointment to tell the patient diagnosis is preferable. 3. If the diagnostic results are negative, saying the good news over the telephone is permitted. 4. Sooner does not mean necessarily better; find out if the patient is ready for the

information. 5. Finding the right place, special office room preferably; if in patient's room, never tell the diagnosis while other patients are present. 6. Ask patient's permission for giving information to his/her family or significant others. 7. Never inform patient/family on corridor. 8. As an informer, never remain standing in front of patients who are seated or in bed. 9. Use your knowledge and skills in breaking bad news. 10. Remember: it is possible to explain the same facts in a way "that causes anger and fear, or optimism and trust".

Breaking bad news is important for good relationship between a patient and the doctor, nurse and the family for the following reasons: 1. To maintain trust. 2. To reduce uncertainty. 3. To prevent inappropriate hope. 4. To allow appropriate adjustment. 5. To prevent a conspiracy of silence.

Most health care professionals dealing with cancer patients, like doctors, nurses and others, dislike explaining bad news, even though it is a very important part of their job. According to Kaye (9), the following are the reasons for their discomfort: 1. Feeling incompetent in communication skills. 2. Getting blamed. 3. Unleashing a reaction. 4. "Failing" the patient by not curing them. 5. Wanting to "shield" the patient. 6. Feeling awkward about showing sympathy as a professional. 7. Being powerless to control emotional stress. 8. Feeling embarrassed about how to behave when someone is very upset. 9. "Not enough time" (although patient satisfaction depends less on time spent than the quality of the interaction). 10. Being reminded of human vulnerability.

But it is important to know and to remember that for all doctors and nurses it is professionally satisfying to develop competence in dealing with the emotional elements of illness.

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SUMMARY

The importance of psychosocial factors in the cancer journey for both patients and their careers has been recognized, yet, there is still a great gap between the theory and the practice. The majority of cancer patients express universal need and stress the importance of having good relationships with health-care professionals and receiving good-quality information. There is still much to do when it comes to informing cancer patients. Many patients do not receive enough information about the prognosis, the alternatives of treatment and the effects of cancer treatment. Most people want information because it has a positive impact on their feelings and attitudes and it helps them to cope with their situation. Health-care professionals must target interventions toward the greatest needs. Interventions must be developed and evaluated to assist patients and their families in dealing with the increased stress they experience as they progress the illness trajectory. By recognizing the importance of social support to patients with cancer and by helping patients maintain this support, health-care professionals, especially nurses, can be the best facilitators in helping them to understand that they are not alone in fighting their disease. Health-care professionals must target interventions toward the greatest needs. Interventions must be developed and evaluated to assist patients and their families in dealing with the increased stress they experience as they progress the illness trajectory.

Profesjonalna informacja, edukacja i porada jako przesłanki jakości opieki nad chorymi na nowotwór

Chory na nowotwór i jego rodzina stają w obliczu ogromnego stresu, wywołanego pojawieniem się choroby i niepewności co do jej przebiegu i rokowania. Mechanizmy radzenia sobie w chorobie nowotworowej są niezmiernie istotne dla osoby chorej na nowotwór i odzwierciedlają sposoby, metody i działania podejmowane w celu zrównoważenia stresu związanego z diagnozą, leczeniem i rokowaniem. Lekarze i pielęgniarki onkologiczne mają znaczący udział w uruchamianiu sposobów radzenia sobie oraz są w stanie wesprzeć chorych i ich bliskich poprzez odpowiednie przekazywanie informacji, edukowanie w zakresie problemów wywołanych zaistnieniem samej choroby czy też spowodowanych zastosowanym leczeniem. Odpowiednie umiejętności profesjonalnych opiekunów, szczególnie dotyczące komunikowania się oraz przekazywania niekorzystnych informacji, stają się w znaczącej mierze wyznacznikiem jakości opieki w chorobie nowotworowej.