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Original Paper

Psycho-oncology: Where Have We Been? Where Are We Going?

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This article reviews the development of the subspeciality of psycho-oncology and its contributions to patient care, encouraging more attention to and research into the care of the total patient: the physical, psychological, social and spiritual aspects of care. The result is enhanced quality of life as the patient is studied in the domains of living that are important, extending across the continuum of care from diagnosis to palliative care. In addition, cancer prevention and early detection depends largely on changing attitudes and behaviours that put people at greater risk. This is an important area of research for psycho-oncologists. In the past two decades, research has contributed to our understanding of the psychological responses that accompany a cancer diagnosis. Oncologists better recognise psychological distress and psychiatric disorders such as anxiety, depression and delirium (in hospitalised patients) as frequent comorbid disorders. The development of valid assessment tools for the patients' self-report has been important. Increasingly, outcome measures in controlled trials of new therapies include quality of life, and no longer look at survival alone. The future will continue to bring new challenges to psycho-oncology as patients face new challenges in treatment. A major aim of the next century will be to bring this integrated approach to all patients in an affordable manner. © 1999 Elsevier Science Ltd. All rights reserved.

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INTRODUCTION

OVER THE past 20 years, psycho-oncology has developed as one of the subspecialities of oncology. This area deals with the two psychological dimensions of cancer: the patients', families' and staff's emotional reactions to cancer and its treatment (psychosocial); and the psychological and behavioural factors that influence cancer risk and survival (psychobiological) [1].

This has occurred as interest in the 'human side' of patients with cancer has increased. The dimensions dealing with the psychological, social, and spiritual were neglected for many years in most countries around the world. The focus was almost totally on the physical aspects of care. Patients' psychosocial problems were usually not addressed in their care. Suffering from unrecognised anxiety and depression was common: confusional states, common with opioid management of pain and vital organ failure, were often not diagnosed and were, therefore, untreated.

Through the activities of a few teams devoted to the psychosocial area around the world, psycho-oncology has become a recognised area of oncology and oncologic research [2]. It is called both psycho-oncology and psychosocial oncology, depending on preference. In Europe, the term psychosocial has been more widely used. However, the area—the 'human' side of cancer—is the essence of its concerns.

HISTORICAL PERSPECTIVE: WHERE HAVE WE COME FROM?

The word cancer was equated with death for centuries because there was no treatment for it until surgical removal became possible after the introduction of anaesthesia in the last half of the nineteenth century (Table 1). The disease was so frightening that the diagnosis was withheld from the patient. It was considered cruel to reveal it, so only the family

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Table 1. Events altering perceptions of cancer*

Decade	Advances in medicine and cancer	Attitudes toward cancer	Attitudes toward death	Psychiatry and psychology
1800s	Mortality high from infectious diseases; tuberculosis common Effective cancer treatment unknown Introduction of anaesthesia and antisepsis, opening way for surgical excision of cancer (1847)	Cancer equals death; diagnosis not revealed Stigma, shame, guilt associated with having cancer; fears of transmission	Patient is “in God’s hands”; physician’s role seen to comfort; “death is part of life”; person dies at home	Concern only with major, mental illness; psychiatrists called “alienists” Psychiatric hospitals largely removed from general hospitals; by 1850s, efforts to bring psychiatry into medicine
1990–1920s	Successful surgical removal of some early cancers Radiation used for palliation American Cancer Society (ACS) started (1913)	In 1890s, efforts in Europe and U.S.A. to inform public of warning signs of cancer Era of home remedies and quack cures for cancer	Doctors assumed authoritarian and paternalistic role, did not reveal diagnosis or medications; “trust me and don’t worry” philosophy	First psychiatric unit in a general hospital, Albany, New York (1902) Psychobiological approach of Adolf Meyer Psychophysiological approach to disease by Cannon
1930s	National Cancer Institute and International Union against Cancer formed (1937)	ACS visitor–volunteer programmes for cancer patients with functional deficits (colostomy, laryngectomy)	Deaths in hospitals; embalming, elaborate funerals; person “only sleeping” as euphemism for death	Beginning psychiatric consultation and psychiatric units in general hospitals Psychosomatic movement begun; strong psychoanalytic orientation
1940s	Nitrogen mustards, developed in World War II, found to have antitumour action First remission of acute leukaemia by use of drugs	Pervasive pessimism of public and doctors about outcome of cancer treatment	Expression of grief encouraged; concern for handling of death Funeral “industry”	Search for cancer personality and life events as cause of cancer First scientific study of acute grief Role for social workers defined in U.S.A.
1950s	Beginning of cancer chemotherapy; first cure of choriocarcinoma by drugs alone (1951)	Debates about the practice of not revealing cancer diagnosis reach the public, who are better informed about issues in medicine	Post World War II concerns about informed consent and patient autonomy	First papers on psychological reactions to cancer (1951–1952); psychiatrists favour revealing cancer diagnosis First psychiatric unit established at Memorial Sloan-Kettering Cancer Center (MSKCC) (1950) under Sutherland
1960s	Combined modalities lead to first survivors of childhood leukaemia and Hodgkin’s disease Hospice movement started Tobacco related to lung cancer	More optimism Survivors concerns are heard Public concern grows for prevention research in cancer	U.S.A. federal guidelines for patient participation in research	Kubler-Ross’s influence important in U.S.A. Thanatology begun with interest in “death with dignity” Behavioural studies of life-style and habits which increase cancer risk
1970s	National Cancer Plan, 1972, with rehabilitation and cancer control, psychosocial included Informed consent for treatment protocols; increased patient autonomy Two cooperative groups, CALGB (Cancer and Leukaemia Group B) and EORTC (European Organization for Research in the Treatment of Cancer) established committees to study quality of life (QOL) and psychosocial issues	Diagnosis usually revealed in U.S.A. and several other countries Guidelines for protection of patients’ rights	Prognosis more likely not revealed First hospice in U.S.A. (1974) Guidelines for care of hopelessly ill—do not resuscitate (DNR) (1976)	First support for psychosocial studies First National Conference on psychosocial research (1975) Psychosocial Collaborative Oncology Group (PSYCOG) began Project Omega (1977–84) Study of children with cancer Psychiatry Service at MSKCC established (1977)
1980s	ACS assisted in development of psycho-oncology; four conferences on research methods ACS-Peer Review Committee established for psychosocial research (1989) Better analgesics and anti-emetics developed Federal Drug Administration in U.S.A mandates quality of life in cancer trials of new anticancer agents (1985)	More cancer survivors Formation of national (U.S.A.) coalition of cancer survivors U.S.A. consumer and women’s movement Concern for quality of life and symptom control increases Pain initiatives for public and professional education	Impact of President’s Commission for study of ethical problems in medicine Health proxy assignment encouraged in U.S.A. U.S.A. physicians required to discuss wishes about resuscitation (DNR)	International Psycho-oncology Society (1984) National and regional psycho-oncology societies formed in U.S.A. Health psychologists contribute to clinical care and research in cancer Development of psychobiological research (psychoneuroimmunology)
1990s	First overall reduction in cancer mortality reported in U.S.A. Increased global interest in palliative medicine; chairs established in U.K., Canada, and Australia Cooperative trials groups include QOL (quality of life) in outcome measures	Increased public concern about cigarettes and cancer Social and legal pressure on tobacco companies in U.S.A. Active smoking cessation research	Public and professional debate about physician-assisted suicide New educational and research interest in care at the end of life (Project on Death in America)	Increasing support for nursing and social work research Third World Congress of Psycho-Oncology (Beaune, 1992) Kobe, 1996, New York, 1996 Behavioural, psychosocial, and psychopharmacological intervention trials

*Adapted from Holland [6].

was given the facts. This has been called the 'conspiracy of silence' which left the patient feeling isolated and alone. The result was a false cheerfulness and deception from others that did not permit patients an opportunity to express their distress and concerns to others. In many countries, the practice of withholding the diagnosis of cancer continues even today, but the tendency toward open disclosure increases as patients become more sophisticated and better informed about medical illnesses.

Despite the fact that cancer is more treatable today and that the number of survivors increases, there is still a pervasive fear that attends a diagnosis of cancer: fear of death, pain, loss of independence or attractiveness, and the suffering associated with progressive illness. Cancer bears a stigma not associated with heart disease, even when the prognosis is the same.

This history, outlined in Table 1 by decades of the twentieth century, shows the changes in cancer treatment and evolving changes in attitude as cancer became more treatable and psychological issues were discussed openly. The first curative treatment was by surgery alone, if the disease was diagnosed at an early stage. For the first time, it made sense to educate the public about the warning signs of cancer and the importance of not delaying out of fear and a fatalistic attitude, when they recognised a suspicious symptom. Radiation became available in the early part of the century, but it carried with it a fear that it was a palliative, not curative treatment.

The National Cancer Institute, founded in the U.S.A. in 1937, has provided a federal model and support for many of the advances in cancer treatment, particularly the development of chemotherapeutic agents. It has, over the years, increasingly supported behavioural and psychosocial research.

By the 1950s, the addition of chemotherapy as a cancer treatment, combined with surgery and radiation, began to impact positively on the survival of children and young adults with several tumours: acute lymphocytic leukaemia, Hodgkin's disease and testicular cancer.

In the U.S.A., the American Cancer Society's development was an important step for cancer education and provision of emotional support. It established the importance of patients who had received a particular treatment, such as colostomy or laryngectomy, preparing other patients to face the same treatment. The Reach to Recovery Programme, which links a woman who has had breast cancer with a woman just being treated, has been a powerful source of support for women. The programme has been established with great success around the world.

Several historical factors have led to greater emphasis on psychological and social issues in cancer. These include: the shifting of attitudes away from fatalism about cancer; the more open disclosure of the diagnosis and, therefore, more open discussion with others; greater dialogue between doctor and patient; discussion with the patient about treatment options and asking for their participation in decision making; the ability to study scientifically the psychosocial domain due to the development of valid assessment tools; and the recognition that cancer prevention and screening depends in large measure on changing behaviours and attitudes.

In recent years, research in psycho-oncology has progressed to the point that it is possible to present a research model that places the various aspects of our efforts into an integrated perspective. Figure 1 notes that cancer and its treatment is the independent variable; the outcome variables are survival and health-related quality of life. A major advance has occurred with the development of validated scales that are based on patients' own reports. Patients can now report their level of function in physical, psychological, social, work and sexual domains of their life. This has been a remarkably active field of research that has developed in the past decade. The expression 'quality of life' is often misunderstood, but it basically means the person's perception of his/her ability to function in meaningful areas of living, after illness, as compared with before.

The mediating variables, noted in Figure 1, are those that are the subject of our psychosocial studies and interventions. We seek to study those personal variables (demography,

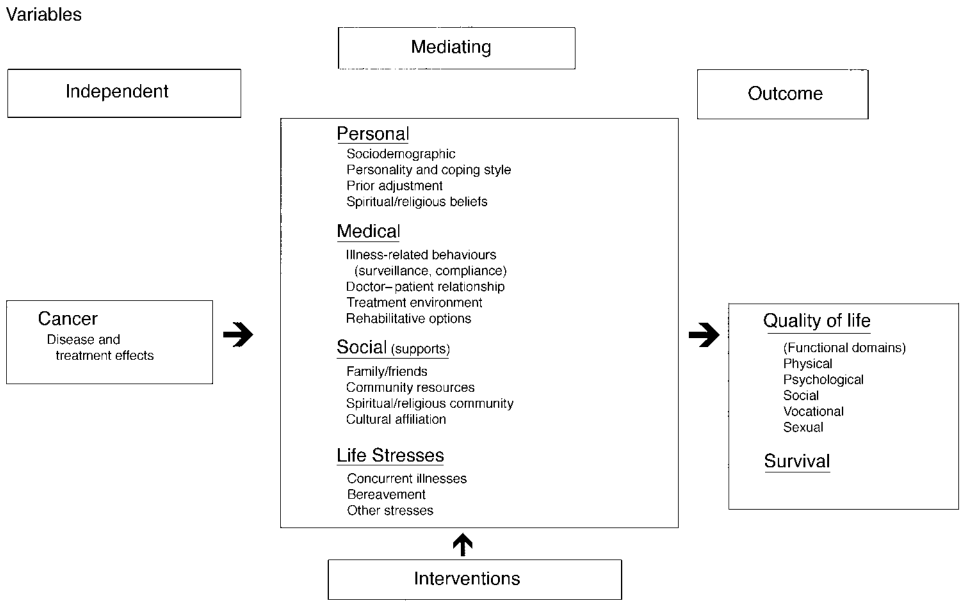

Figure 1. Model of research in psycho-oncology. Adapted with permission from Figure 20.1 [11].

coping skills, beliefs, and personality) that impact upon outcome. The medical variables measure the impact of doctor–patient relationships, the treatment environment, and rehabilitation options, upon coping. The importance of social support for the person who is ill emerges as a critical factor in coping, as do the presence of other stressors at the time of illness.

Using this model, it has been possible to evaluate patients' levels of distress and to determine those who would benefit from psychosocial interventions. Studies have shown repeatedly that levels of distress are lowered and coping and self-esteem improve with a range of interventions, both group and individual therapies [3, 4]. Studies which have screened for levels of distress in patients attending oncology clinics show that approximately one-third have significant levels of distress, but far fewer are identified by the medical staff and are referred for psychosocial help [3, 5]. Patients are reluctant to tell the doctor that they are anxious or depressed, in part because they do not want to bother the busy doctor, but also because there is a stigma associated with anything 'mental', 'psychological' or 'psychiatric'. Doctors also do not want to ask about distress because they are hurried and they, too, fear the patient might be annoyed if they were asked about this area. Through the National Cancer Centers Network (NCCN), a multidisciplinary panel has worked on this problem, suggesting using the word 'distress' as one that is not stigmatising and to which a patient can respond, as they do to a 0–10 pain scale: "How is your distress on a scale of 0–10?". A response of 5 or greater should trigger a question from the oncology team as to the cause of the distress (for example physical symptoms, psychological, family, spiritual or practical). This becomes the algorithm for referral to mental health, social work or pastoral counselling [5]. The result is that patients who are in need of psychosocial care can get to the resources that are available in most cancer centres, such as nurses, social workers, psychologists, psychiatrists and pastoral counsellors.

Most cancer centres today have a small psychosocial unit that is responsible for managing the psychological and social problems of patients and families, as well as teaching medical staff about these issues. If the unit is large enough, there should be opportunity for training of medical and psychological staff in identification of the distressed patient and communication with patients. Research studies are a desirable part of the unit's agenda, exploring questions raised by observations from clinical care, and contributing to translational research.

A person from any one of the disciplines giving supportive interventions may direct the psychosocial unit [6]. It is important that all the disciplines giving supportive services constitute a team with triage of cases to the proper resources. Disciplines not represented in the group should be available by consultation.

THE FUTURE CHALLENGES: WHERE ARE WE GOING?

The new millennium provides a superb opportunity to review our experience and to look forward to directing the field in the most useful way. In terms of clinical services, the traditional focus of psycho-oncology has been at the time of diagnosis and while receiving active treatment. It is important to extend our focus: to survivors, palliative care; and to the 'worried well': people who are healthy but recognise that they have a high risk of developing cancer by virtue of genetic risk, testing, or a positive biomarker. These are emerging areas in which the psycho-oncologist should become an integral part of the clinical and research teams.

In palliative care, the treatment goals are to address not only the physical but the psychological, social (family) and spiritual domains. It becomes clear that mental health professionals should be involved to a much greater degree in providing clinical services, consultation and training of medical staff in giving maximal attention to the 'suffering' component of care. The judicious uses of psychotropic drugs are extremely effective in managing anxiety, depression, and confusional states, and they serve as adjuncts to pain management. Consultation in proper use of these drugs is a critical part of palliative care.

At the other end of the spectrum, we must address far more aggressively those individuals who are healthy, but who are acutely aware of their heightened cancer risk because of genetic history. Women often fear breast cancer to a high degree, based on their family histories. Genetic testing adds a new dimension of anxiety about learning whether one is a carrier or not—both for the individual concerned and for family members. Many healthy people also have unhealthy lifestyles and habits which increase cancer risk. Only by studying ways to change behaviour, such as cigarette smoking, can we begin to reduce unnecessary exposures and reduce cancer risk.

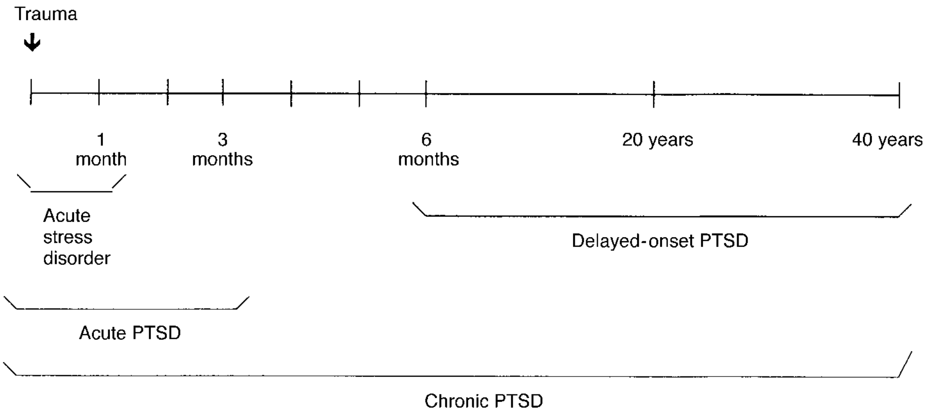

Figure 2. Time course and Post-traumatic Stress Disorder subtypes.

As long-term survivors increase in numbers, we will need to learn more about the psychological sequelae of arduous cancer treatments. Post-traumatic Stress Disorder (PTSD) and stress symptoms are common among mothers whose children are treated for cancer, and they persist after treatment has ceased [7]. Patients who complete stem cell or bone marrow transplant have a high frequency of PTSD symptoms early on after finishing treatment, which decreases over time. Patients who have had a prior trauma find post-traumatic symptoms recur at the time of stressful cancer treatment. Figure 2 shows a conceptual model for how PTSD appears clinically. This model suggests the need for further study.

In clinical care terms, it is important that standards of care be delineated and treatment guidelines be developed. For example, how many psychosocial staff members are needed to adequately care for a clinic of 50 patients? The Canadian Association for Psychosocial Oncology is developing standards for services. The NCCN has fostered the development of standards, a triage system and treatment guidelines for mental health, social work and pastoral counselling [5]. Regulatory bodies overseeing cancer care will need to watch over these areas as they evaluate and approve centres for quality cancer care.

In terms of training, there are currently few programmes in the world that offer both clinical and research training. There is a great need for support for several centres worldwide, which can offer a model curriculum for the training of psycho-oncologists who can give clinical care and conduct research and training [8, 9].

The future of the field will depend on the recruitment of bright young clinicians and researchers into the field, and support to retain them in their career choice. The range of problems to study is broad, from prevention to palliative care. Prospective young professionals, with an interest in medicine and psychology, should find this a challenging area in the next two decades. The assessment tools are in place and there is greater appreciation of the 'human' side of cancer. The challenges of new cancer treatments will confront patients with new psychological issues, which will, in turn, become challenges for psycho-oncologists. The opportunities are exciting for new developments in the future, as more attention is being given to this 'human' side of patient care.

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