

Psycho-Oncology for the Clinician

The Patient Behind
the Disease

Shulamith Kreitler

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*The book is dedicated to Jimmie C. Holland
(1928–2017), a pioneer in Psycho-Oncology*

Preface

The appearance at the present time of a book with the title *Psycho-Oncology for the Clinician: The Patient Behind the Disease* requires some kind of explanation. One could wonder why is a book about Psycho-Oncology written at a time when cancer care is becoming increasingly complex as is and, on top of it, expensive at a barely imaginable degree. Neither national institutions nor private patients can cover all expenses. Do we need another target of expenses? Furthermore, one may wonder why deal with Psycho-Oncology at a time when breakthroughs in medicine loom large, spotlighting genetics and immunology, which are indeed expensive but promise recovery, while Psycho-Oncology – what does it actually promise?

The answer is simple – it promises and enables better medicine. There is a long list of potential results. Here is a sample of some of its benefits: better adherence of the patients with the medications, better cooperation of the patients with the treatments, higher satisfaction of the patients with the care they get, easier communication between the clinicians and the patients, lower levels of stress and especially of empathic fatigue in the health carers, better quality of life for patients and family members during treatment and in the survival period, and lower levels of anxiety and of depression in patients especially during crisis phases. In addition, there are no negative side effects to the service of Psycho-Oncology, and it is a cheap service which requires no drugs or mechanical devices, only skilled and trained practitioners.

Yet, Psycho-Oncology is not a fully accepted and legitimate component of cancer care. Even though it is already available in most hospitals and clinics, patients do not always address this service, and, in general, it is not considered as an essential component of cancer care.

So, this is where the message of this book comes in. The book is designed to clarify two main points. One is that Psycho-Oncology is an essential component of cancer treatment and not just a luxury which one may or may not use, at will. As such, it is a major constituent that should be integrated into personalized medicine. It fits in perfectly with what personalized medicine is expected to be, namely, an approach that strives to improve the outcomes and use of medicine by tailoring it to the relevant needs and characteristics of the individual patient. The book is designed

to show that psychological needs of the patient are an important aspect that should be considered for optimizing the effects of cancer treatment, no less than genetic, immunological, physiological, and other medical features that are often considered as necessary components of personalized medicine.

The second point is that Psycho-Oncology has become a real science. It has started as a human support-based approach designed to help cancer patients and has evolved into a full-fledged flourishing and dynamic scientific discipline, which has carved for itself a specific space, affiliated with both medicine and psychology yet autonomous in regard to both. However, this scientific breakthrough has not brought in its wake a loss of the human support component of Psycho-Oncology. Quite on the contrary, it has enhanced it.

The audience for which the book is designed is quite broad. The book is intended for clinicians, so that they become updated concerning the benefits and scientific bases of Psycho-Oncology. As a result, they are expected to consider it in treatment and encourage patients to use it. It is intended for patients so that they do not avoid it but rather carve a space for it in the course of their journey through cancer, because a patient who has been exposed to Psycho-Oncology has an easier life and less suffering than a patient who was not. It is intended for clinical researchers in oncology so that they become aware of potential interactions between physiological parameters and psychological variables which they could consider. It is intended for policy-makers to become convinced that Psycho-Oncology is important enough to provide some financial resources for its development and availability. It is intended also for psycho-oncologists so that they have a chance to become fully aware of the treasure they have at hand to offer the patients and clinicians.

The information presented in the book is based on scientific studies and on the personal experience of the author who has been working continuously with cancer patients and their families for about 40 years, has developed two Psycho-Oncology centers in two major hospitals in Israel, has done research work in Psycho-Oncology, and has taught Psycho-Oncology to healthcare professionals of all kinds. Thus, the style is readable, and the contents is grounded in scientific sources enlightened and clarified by personal experience.

The author's hope is that the book will contribute to the further scientific development of Psycho-Oncology, to expanding its use as a treatment modality, to strengthening its status as an essential component of cancer care, and to promoting the acceptance of Psycho-Oncology as the new evidence-based constituent of personalized medicine in oncology.

My heartfelt thanks are due to all the doctors, nurses, health professionals of all kinds and primarily the patients of all ages and diagnoses and in so many countries who have taught me and let me learn about cancer and about how to live with it and despite it.

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Chapter 1

The History of Psycho-Oncology



Introduction

One may wonder about the meaning of history in regard to Psycho-Oncology. Why examine the history of Psycho-Oncology when it is evident that Psycho-Oncology has always existed, actually from early times when one individual approached a cancer patient with a smile or a gentle touch. Yet, it is no less evident that nowadays Psycho-Oncology includes much more and has a completely different status. History is designed to bridge the gap between the early times and the astounding situation at present, when – at least in the Western world – it is hardly conceivable that a cancer patient does not get psychooncological treatment as part of the overall medical handling of his or her case.

But if Psycho-Oncology has always existed, why is it that it has taken such a long time for it to get recognized formally?

Reasons for the Delay in the Development of Psycho-Oncology

With the best of intentions, it would be possible to identify the mid-1970s as the time when Psycho-Oncology came to life in a formal sense. There are reasons of different kinds that have contributed to the difficulties in the formation of Psycho-Oncology.

The Status of Medical Oncology One major set of reasons has to do with the status of medicine in regard to cancer. The speciality of medical oncology is relatively young [1]. It is only in the 1900s that successful removal of early tumors was carried out and radiation introduced as an oncological treatment modality. The 1940s witnessed the advance in the treatment of lymphoma (with nitrogen mustards) and of acute leukemia (with aminopterin). The big breakthrough came with the advent of chemotherapy in the early 1950s [2, 3]. These are just glimpses into

the slow and hard development of medical oncology that have given rise to the first National Cancer Plan in the USA in 1972. It is understandable that prior to the development in medical oncology, there was no possibility, space, or option for Psycho-Oncology. The beginnings of Psycho-Oncology took shape in those same years in the form of studies of quality of life of cancer patients (European Organization for Research and Treatment of Cancer [EORTC], founded in 1962) and the establishment of full-time psychiatry service at the Memorial Sloan Kettering Cancer Service (1977). These early projects and the many others heralded by them could barely take place without weakening of the taboo characterizing cancer, the initiation of large-scale clinical trials in oncology, the beginning evidence for successful cures with chemotherapy, and development of different medical modalities and drugs for treating cancer patients, followed by the developments in immunology, molecular biology, and genetics that enabled spectacular breakthroughs in medical oncology [4].

The Taboos Regarding Cancer Another important set of reasons for the delay in the development of Psycho-Oncology are the various taboos connected with cancer. All diseases are probably unpleasant concepts, but some are considered as outright taboos. Mental disorders, sexually transmitted diseases, and notably cancer are major items on this list. Cancer has been viewed as taboo primarily in the long periods when there was no treatment for it, no hope, and no respite from the pain and other associated symptoms. In addition to the suffering, cancer patients were burdened with guilt, shame, and the pressure to hide their disease and the unsightly lesions that sometimes appeared. Cancer was not something to be spoken about, by the patient or the family. Only about the 1950s there began the debate about whether cancer diagnoses can at all be revealed to patients. As long as the barriers of denial and silencing prevailed, there was barely a chance to approach patients psychologically, not to mention the possibility of studying the psychological correlates of cancer. It is possible that the stigma accompanying cancer may be grounded also, at least to some extent, in the association of cancer with death. Actually, the stigma overshadowing cancer is still not completely deleted or overcome in the case of all patients and families in all countries. The taboo was replaced by suspicions that discussing cancer openly may harm patients. These attitudes, shared by lay individuals as well as by health professionals, formed a difficult barrier against the development of Psycho-Oncology [5].

The Scientific Status of Psycho-Oncology That is where a third set of reasons that delayed the development of Psycho-Oncology comes in. This is the limited amount of evidence-based information that existed in regard to Psycho-Oncology. This issue should not be considered as constituting a particularly difficult barrier. However, it turned out not to be easily surmountable. Evidence-based information requires empirical research, and this kind of scientific activity requires among other things getting information about different aspects of cancer from patients and their families by means, such as administered questionnaires, observations, and interviewing, performed only with the patients' full legally established informed con-

sent. Limitations concerning addressing the issue of cancer directly or indirectly render empirical research difficult and slow due to the reluctance of the patients and families to participate in the studies. The reluctance was enhanced, particularly in the early stages, by the lack of experience of patients and families to discuss openly the emotional and other personal aspects of cancer [6].

Negative Attitudes Toward the Relations of Psychology with Cancer A fourth set of reasons that slowed down the development of Psycho-Oncology has to do with the negative attitude of patients toward the involvement of psychology in cancer. Considering psychology as a means for understanding or treating cancer evokes the association of mental disorders or illness. Mental disorders have been feared and avoided by people for generations [7, 8]. Individuals with mental problems were no less stigmatized than cancer patients and have often been blamed, punished, and ostracized because of their problem. Even nowadays, individuals who may have mental problems are avoided and often treated differently [9]. Hence, cancer patients would be reluctant to admit that possibly they have psychological problems in addition to their cancer.

Moreover, psychological issues tend to be interpreted as signs of weakness, portending the inability of the patient to handle one's problems. Since cancer is often related to quite serious difficulties of coping, cancer patients are afraid that admitting to psychological problems would weaken their coping ability and would make others consider them as helpless and dependent.

Underlying these negative attitudes to psychology, there is another more general problem which may be described as the unclarity of the relations between psychology and physical disorders in general, or in simpler terms: What does psychology have to do with cancer at all? It is really quite surprising that this issue is still alive and seems relevant.

The issue is a manifestation of basic theoretical shortcomings in the conception of the image of the human being, reflecting on science in general and on medicine and psychology specifically. Basically the problem arises from lack of conceptual clarity about the relations between the constructs of body and mind. Tracing the changes in the conceptualization of *body-mind relations* in the behavioral sciences reveals five major phases [10]. They will be mentioned here because they may shed light on understanding the status and history of Psycho-Oncology.

The *first phase* of the body-mind relations is characterized by the view that there is nothing but the body. This approach describes the status of oncology prior to the beginnings of Psycho-Oncology. Even at present it seems to be shared by medical oncologists and probably also by an undefined number of cancer patients. It is apparently a simple approach that relieves both doctors and patients of the need to deal with psychological issues that probably seem to them controversial, unsupported by any objective evidence, and possibly harmful for patients. The major shortcoming of this approach is that it denies patients the possibility of getting the psychological support which they may need and which could help them. A possible result of this approach is that cancer patients turn for support to alternative treatments and sometimes to various highly doubtful methods without consulting with their

doctors and often without informing them. It cannot be ruled out that the results could be harmful for the patients.

The *second phase* is marked by the conception that the mind is the only relevant factor. Although this approach seems to be favorable for Psycho-Oncology, it does not do good service to Psycho-Oncology because it is based often on unfounded beliefs, such as that recovering from cancer can be attained by the mere desire to be healthy or by adhering to a certain cult or a certain healer. Another danger associated with this approach is that patients would refuse to get medical treatment either because they view it as superfluous or useless or because it would indicate the incompleteness of their faith in the nonmedical treatments they endorse. This approach is strongly rejected by oncologists and is probably espoused only by a minority of cancer patients.

The *third phase* in conceptualizing the body-mind relations is that both body and mind exist and are operative, but they function in parallel tracks. It seems that many oncologists as well as patients have chosen to support this conception. It seems to be a comfortable conception because it consists in a liberal acceptance of the major entities – the medical and the psychological – without however bothering about their possible interactions or mutual influences. The implication is that what happens in the body, including even serious physical disorders, does not have much to do with the psychological plane of functioning. And the psychological phenomena, however emotional and important they may seem to observers and to the patients themselves, do not have anything to do with the physical phenomena. Hence, the impact or manifestations of the physical level on the psychological one as well as those of the psychological level on the physical one may be safely disregarded regardless of how impressive or convincing the mutual effects may seem or be experienced by the individual or by observers. This approach enables proceeding with research and therapy on the purely medical level as well as on the psychological level, without considering the implications of the empirical or therapeutic results on one level in regard to the other level. Hence, in the framework of the third phase approach, it is difficult to identify a right niche or space or field for examining the interactions between body and mind or, for that matter, the possible effects of psychological factors on one's physical health and state and of the physical phenomena on one's psychological status. This conclusion is of particular importance for research in Psycho-Oncology because it limits the theoretical space of psychooncological variables only to the sphere of psychology or at best it allows to consider them as correlates of physical variables or phenomena, but not as causes or results.

The *fourth phase* of body-mind relations is based on the assumption that both body and mind exist and that they function in interaction, namely, the phenomena on each level may be considered as affected by those on the other level and as affecting them. Adopting this approach is definitely less comfortable theoretically and practically than the approach of parallelism of the third phase. The reason is that it requires considering – both in research and therapy – the mutual effects of the medical and psychological levels. This provides a new opening and challenge particularly for Psycho-Oncology. The challenge consists primarily in the need to create theoretical models for identifying and defining the intervening constructs and

mediating variables through which the psychological effects get translated or transferred from the psychological to physical phenomena relevant for disease and health in general and for cancer in particular. The potential routes include biological factors, such as molecular reactions and cellular responses in the immunological and genetic frameworks. The new approach gave rise to new theoretical frameworks enabling the exploration of the psycho-physical interactions, mainly psychoneuro-immunology [11, 12] and biopsychosocial models [13–16], or examining the contribution of psychological factors, e.g., cognitive to physical disorders, as identifying psychological risk factors for cancer [17] or examining the impact of physical phenomena on psychological and emotional reactions, as identifying tumor characteristics evoking depression [18] or the impact of chemotherapy on cognitive impairment [19]. Contributions from health psychology [20], psychosomatics [21], cognitive-behavioral approaches [22], and psychopharmacology [23] have been particularly productive. Exploring the connections between the physical and psychological phenomena sometimes provides initial support for the view that body and mind are actually identical and under certain conditions constitute merely different manifestations of the same core energy or material.

The interactional view of body-mind is favorable for scientific research in each of the spheres of medicine and Psycho-Oncology. It encourages exploring the psychological effects of physical phenomena, such as the impact of the occurrence of cancer and of different oncologic treatments on the patients' quality of life [24, 25]. It also enabled developing and applying various psychological interventions for helping cancer patients.

Development of Psycho-Oncology

The foregoing introductory section highlighted some of the major reasons that delayed the development of Psycho-Oncology. In addition, it clarified that the development of Psycho-Oncology has to be traced along three different intertwined tracks: the scientific track, the applied track, and the organizational track.

The Scientific Track of Development

As noted, there have been various difficulties that limited the availability of cancer patients as subjects in research. Some had to do with the reluctance of the patients themselves, due to suspicions about incomplete privacy, or no desire to devote time during their disease to something that does not seem to them to be of equal importance to medicine. A painful situation arises not infrequently when patients agree to participate but leave the questionnaires incomplete or withdraw too soon from the studies. Other difficulties of recruiting patients for studies may have had to do with regulations in clinics and hospitals based on requirements of ethics committees that

made it sometimes overly difficult to recruit patients for studies that involved no more than validating a simple questionnaire. Further, the elaborated models of experimental research that have been developed in psychology proper could not be transferred without changes to the field of Psycho-Oncology, because of the special characteristics of patients with chronic diseases in general and of cancer patients in particular. Psychosomatic research could not provide much help because the research models it has developed up to the 1970s in regard to other illnesses, particularly asthma, rheumatoid arthritis, gastric ulcer, and hypertension, were either too crude or inapplicable to cancer. Hence, it is evident that psychooncologists had to elaborate new research models for their scientific studies, and this task sounds simpler than it actually is.

In reality devising adequate research models in Psycho-Oncology required several methodological decisions. One of these referred to defining *research groups*. This involves deciding whether it is possible to combine in one sample patients with different cancer diagnoses, or patients in different disease stages, or patients in different phases of treatment (e.g., pretreatment, after the first or second cycle of treatment, patients in remission). A related issue concerns the definition of *control groups* in studies with cancer patients. Healthy control subjects may not always provide ideal comparison for subjects with cancer when the goal is to identify characteristics of the cancer patients. Additionally, blinding is particularly difficult to achieve because consent procedures require participants to understand differences in treatments, which in Psycho-Oncology may often have obvious implications. Another important methodological issue concerns the *control variables* that need to be considered, ranging from kinds of treatments to duration of treatments, stages of disease, comorbidities, lifestyle factors, and the various demographic characteristics. A fourth research issue concerns the selection of adequate, available, and relevant *medical correlates* that are sometimes required or advisable for psychological variables. The need arises for identifying and assessing physiological variables especially when the psychological ones are not as unambiguous as desired, for example, one may wonder whether cognitive impairment following chemotherapy is a manifestation of lack of concentration or interest or a brain-grounded phenomenon. A fifth methodological issue concerns the preparation of relevant as well as valid and reliable *research tools* for Psycho-Oncology. Very early it became clear that psychosocial research with cancer patients requires devising adequate tools for cancer patients. Since the standard tools in psychology are mostly inadequate for Psycho-Oncology, new tools for assessment and for intervention have to be developed for specific needs or issues concerning cancer patients, such as doctor-patient communication or attitudes toward dying. Major developments in this field included the measures of quality of life questionnaires by the European Organization of Research and Treatment of Cancer (EORTC) [26], the Functional Assessment of Cancer Therapy Scale [27], the Memorial Symptom Assessment Scale [28], the Distress Thermometer [29], McCorkle's Symptom Distress Scale [30], the Brief Symptom Inventory (BSI) [31], Fear of Recurrence Inventory [32], Decisional Conflict scale [33], the play-performance scale for pediatric patients [27], and tools for assessing various psychological phenomena in children with cancer patients [34, 35]. Meaning-centered psychotherapy [36], dignity therapy [37] for advanced and palliative cancer

patients, and psychoeducational interventions for melanoma patients [38] are examples of interventions developed specifically for cancer patients.

Despite all these theoretical, methodological, and practical difficulties, Psycho-Oncology investigators proceeded courageously on the track of development, trying as best as possible to explore new territories and adhere to the strict criteria applied to evaluating studies considered as potential candidates for inclusion in Cochrane reviews.

Clinical Application

Clinical applications in Psycho-Oncology constituted originally a new unknown and unexplored territory. It was not even evident that cancer patients need psychooncological help or, for that matter, that there may be a psychological aspect to any medical patients with chronic diseases. It seems that until the 1900s, physicians were unaware that chronic medical patients may suffer from emotional difficulties, including depression, stress, and adjustment problems. One of the pioneers in this domain was Adolf Meyer who encouraged medical colleagues and students to consider “the whole person,” thereby facilitating the integration of psychology into medical practice. The first psychiatric ward for patients with chronic physical diseases opened in Albany, New York, in 1902 [4].

In the 1930s psychiatric consultation began to be introduced into medical wards. At the same time psychosomatic conceptions were being developed in the framework of psychoanalysis by investigators such as F. Alexander, E. Simmel, E. Witkower, and others who started treating with psychoanalytic tools individuals with different somatic disorders, mainly bronchial asthma, essential hypertension, peptic ulcer, ulcerative colitis, rheumatoid arthritis, and neurodermatitis [21]. Although the results were not always impressive, and cancer was not one of the disorders treated psychotherapeutically, there was enough evidence in the procedures to provide impetus for attention to the suffering of cancer patients. One of the early most impressive ventures was done by Loma Feigenberg who started treating psychotherapeutically patients with advanced cancer [39]. He also promoted psychological support for the dying, which constituted part of the emerging interest in providing psychological help to dying cancer patients in the framework of palliative care in hospitals and hospices [40, 41].

Nurses filled an all-important role in the development of the trend to supply psychosocial support to cancer patients. Their personal, empathic, and professional support for cancer patients on an almost daily basis formed an important source of help to patients and inspired other healthcare professionals.

A completely different source of inspiration for developing psychooncological help for cancer patients consisted of the sporadic self-help groups organized initially informally by cancer patients, outside the formal frameworks. The interest and enthusiasm these attempts evoked sent a clear message to those who could take care of organizing psychooncological help top-down.

The awareness of the need for psychooncological services was further enhanced by different advocacy groups and especially by publication of studies and surveys of specific issues concerning cancer patients, such as responses of patients to radical surgery, reactions to truth telling to patients and families, and side effects of chemotherapy, which resulted from developments in medical oncology.

A further factor that enhanced the need for psychooncological clinical work was the development of palliative care in hospitals and in hospices. Taking care of the dying required professional devoted work of many health professionals, including psychosocial experts.

Integrating psychooncological treatment into the formal regular medical treatment of cancer was not an easy process. The barriers consisted partly of the explicit but more often implicit resistance of doctors to let nonmedical specialists invade the formal frameworks of medical practice. An anecdote that may illustrate how difficult the situation was is provided by the fact that the first position confirmed for a clinical psychologist in a medical hospital occurred as late as 1938 in Vienna (the psychologist was the late Hans Kreitler). In addition, there were difficulties related to absence of locations, funding, and procedures. It is only slowly that the so-called consultation-liaison psychiatry experts were replaced by providers of psychooncological support. When the barriers were gradually set aside, there began a trickle of helpers that consisted of psychologists, social workers, reinforced in time by spiritual experts, art therapists, play therapists, experts in mindfulness meditation and yoga, as well as volunteers of all kinds. Alternative practitioners joined in but only later in the formal frameworks as departments in the hospitals, clinics, and sick funds.

Concerning psychologists there was a problem of professional education. Psychotherapeutically educated psychologists were primarily schooled in regard to patients and problems of personality disorders and mental health. This professional background was not only inadequate for treating cancer patients but actually limited the responsiveness of cancer patients to psychologists. Contact with psychologists was considered initially as suggesting that the cancer patients were mentally deranged. This attitude subsided only when psychologists began to be trained in the framework of the newly formed discipline of health psychology.

Clinical work by increasingly psychosocially trained professionals led to devising special interventions and psychotherapeutically oriented programs. The *Handbook of Psychotherapy in Cancer Care* [42] presents some extraordinary contributions in this domain. The text *Pediatric Psycho-Oncology* [43] presents some interventions designed specifically for pediatric cancer patients. Most of the interventions are modifications of programs and procedures standard in psychology, such as cognitive-behavioral therapy. But some are particularly targeted for cancer patients, such as dignity therapy. The different intervention programs are based on the basic psychotherapeutic principles, such as empathy and acceptance, but manifest as well adaptations to the specific issues of cancer, often including flexibility in approach, and involvement of family members, as well as focusing on problems that may concern cancer patients, such as meaningfulness of life or adjustment to life under different or uncertain conditions [36–38].

Organizational Development

The scientific and clinical development of Psycho-Oncology required a parallel organizational development on which it partly depended. Organizational developments consisted of several major steps that are necessary for defining and promoting Psycho-Oncology. These included mainly mobilizing and training professional healthcare workers and gaining for Psycho-Oncology the formal status and the means that would ensure the possibilities for providing cancer patients the needed and best Psycho-Oncology services. The following steps are all necessary and important and have all been done, although not necessarily in the cited sequence and often in interaction and collaboration with each other.

One major task was promoting and establishing formal professional societies for defining standards of practice, promoting the activities and status of Psycho-Oncology, and mobilizing professionals for the cause. Another step consisted in establishing research units or centers for promoting investigations and experiments in Psycho-Oncology. An important step focused on promoting the dissemination of information about Psycho-Oncology in the form of publications, journals, scientific conferences, seminars, and workshops. This led to the development of a curriculum for Psycho-Oncology representing major findings, approaches, conceptions, and practices, enjoying the support of the majority of Psycho-Oncology practitioners and investigators. A further important goal referred to getting formal recognition on the national levels and then from international organizations as well (e.g., the WHO or the UN). It was also necessary to obtain recognition and raise the status and development of Psycho-Oncology as a profession by promoting the establishment of units, programs, and departments in universities and in other institutions of higher learning devoted to researching and teaching of Psycho-Oncology in academic frameworks. All these means are necessary in regard to each discipline but have been mandatory especially in regard to Psycho-Oncology which has not been identified as a profession, and there has been no formal framework within which it could be placed and thrive.

Since the 1900s there has been a slow development of Psycho-Oncology in the organizational sense, which has become faster and also more noticeable after the 1950s. In the 1970s there have been large important Psycho-Oncology-inspired projects in different countries, such as smoking cessation and sunscreen protection in Australia. At the same time small groups of researchers of Psycho-Oncology formed in the UK, Belgium, Sweden, Australia, and Canada. Thus, a psychosocial research unit devoted to breast cancer was established by psychosocial investigators at the King's College Medical School in the UK in 1971; the multidisciplinary Cancer and Leukemia Group B (CALGB) supported by the NCI national clinical trials group was formed in 1976 in the USA; a psychosocial research unit, established in Amsterdam by Fritz van Dam in 1976, dealt with developing quality of life assessment tools (EORTC) that contributed to the assessment of outcomes in clinical trials [4].

An important development was the confirmation in 1972 of the War on Cancer Act by President Nixon which established the Division of Cancer Control and

Rehabilitation (DCCR) that provided the possibility of applying for grants for supportive care for cancer. At the same time period, different palliative care projects and units were formed, for example, the Omega Project by Weisman and Warden in the MASS General Hospital in the USA [40] and the end-of-life care by Cicely Saunders in the UK [41], who is credited with establishing the St Christopher's Hospice [44].

Organizing psychosocial oncology societies constituted a further step toward promoting the accreditation of Psycho-Oncology. Thus, the British Psychosocial Oncology Society was formed in 1982, the American Psychosocial Oncology Society in 1986, the Canadian Association of Psychosocial Oncology in 1985, the French Society of Psycho-Oncology in 1982, and the Dutch Society of Psychosocial Oncology in 1993. Societies were formed also in other parts of the world, for example, in Brazil in 1992, in China in 2006, in Japan in 1987, in Israel in 1992, and in South Korea in 2006. Most societies welcome members from across the disciplines, ranging from oncologists and psychiatrists to nurses or from psychologists to social workers and pastors, all who are involved in education, research, and caring for cancer patients and those who care for them.

Very early the International Psycho-Oncology Society (IPOS) was established. At present it includes as members 28 national societies from all over the globe and about 6000 professionals in over 40 countries. In September 2007, the IPOS Board of Directors and participants in the meeting of national societies voted to establish an IPOS Federation of Psycho-Oncology Societies which includes 26 member countries. IPOS is a member organization of the Union for International Cancer Control (UICC) and a partner of the World Health Organization (WHO) [45].

The psychosocial oncology societies promote the interest of psychooncologists and of Psycho-Oncology. They organize national meetings and international congresses since 1992 in different countries, thereby encouraging and promoting the presentation and dissemination of scientific – theoretical and applied – information and contacts between psychooncologists [46]. Training was promoted, for example, in the form of IPOS-sponsored online lecture series delivered by experts and in the framework of the Psychosocial Academy by workshops offered about themes, such as Research Methods in Psychosocial Oncology, Integrating Hypnotic Approaches in Cancer and Palliative Care, Communication Skills: Concepts and Teaching, and Screening for Distress: The 6th Vital Sign.

The societies promote also the development of guidelines and implementation of standards of care in Psycho-Oncology [47–49]. In 2010 IPOS defined the following standards of care in Psycho-Oncology which function as a kind of manifest for Psycho-Oncology: “Psychosocial cancer care should be recognised as a universal human right; Quality cancer care must integrate the psychosocial domain into routine care; and Distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain.”

Societies, organizations, or speciality units devoted to Psycho-Oncology were formed also in the framework of some of the disciplines of health carers dealing with cancer patients. Most notable are the Association of Oncology Social Work, the Oncology Nursing Society, and the European Health Psychology Society.

An additional track of development concerned education in Psycho-Oncology. When the amount of studies relating to Psycho-Oncology increased, the evidence-based information began to accumulate. *Psycho-Oncology*, the first international journal in the field, was published in 1992. The *Handbook of Psycho-Oncology*, the first reliable and comprehensive text in the field, was published in 1989 [50]. The updated editions followed later and were joined by other important handbooks [51, 52]. A standard curriculum for Psycho-Oncology was formed, and the basics of this new profession were taught in teaching rounds, web seminars, workshops, national conferences, and numerous publications.

The recent stage of development in regard to education concerns the inclusion of Psycho-Oncology in university programs. The first department of psychiatry and behavioral sciences that had an institutional academic status was established at the Memorial Sloan Kettering Cancer Center in 1995. Over the years more than 350 professionals in Psycho-Oncology were trained in that center. At present there are research units devoted to Psycho-Oncology research in many universities, for example, the Psycho-Oncology Research Unit at Aarhus University; Psycho-Oncology and Subjective Health Measures Research Group that unites French-speaking researchers (oncologists, epidemiologists, psychiatrists, psychologists, psychometricians, social scientists, health economists, and statisticians) from France, Switzerland, Italy, Germany, and Belgium; the National Research Center for Hematology in Moscow, Russia, dealing with Psycho-Oncology in regard to hematological patients; and the Department of Medical Decision Making at Leiden University in the Netherlands. The organization of Psycho-Oncology Research Centers in Europe (PoCoG) includes research centers in 11 countries in which research in Psycho-Oncology is being conducted. Additionally, there are a fair number of universities that offer graduate and postgraduate studies in Psycho-Oncology on the master's or doctoral levels, e.g., University of Dublin, Bristol, McGill, and Colorado.

Some Concluding Notes

If one considers that in the early 1900s modern medical oncology barely started to appear and that there was yet no sign of awareness for the psychological needs of cancer patients, the change that has occurred in regard to Psycho-Oncology is nothing less than miraculous. When professionals in the field started to refer openly to the psychological aspects of cancer, there was as yet nothing: no conception, no constructs, no findings, no framework, no procedures, no profession, and not even a definition of a profession. At present, it is undeniable that there is a firm scientific basis for Psycho-Oncology, there is a research methodology, there are guidelines for psychooncological care and interventions, and there are a great many professionals from different disciplines devoted to application, research, and education of Psycho-Oncology in most countries of the world. Considering the staggering numbers – all running in the millions – of cancer patients at present, of the survivors, of those who

die, and of the newly diagnosed cases per year in all countries worldwide, it is barely possible to imagine the load of suffering caused by this disease which is a major cause for death at present. Psycho-Oncology is one discipline devoted to, targeted for, and applied in regard to this kind of problem and suffering. It has proceeded along the multiple tracks of development, being guided and responding to bottom-up and top-down influences, discovering on the way the variety of needs of cancer patients, ranging from emotional to instrumental, from social to spiritual. On the basis of its remarkable development in the scientific sense, in clinical applications, and in terms of organization, it has become a major focus of assistance and hope. As long as cancer is not yet completely cured or eliminated, Psycho-Oncology is one venue or tool for proceeding toward attainment of the commonly shared goal of providing adequate psychosocial care to every person affected directly or indirectly by cancer in any corner of the planet.

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Chapter 2

The Special Characteristics of Oncology and Psycho-Oncology



Psycho-Oncology is one of the first domains of health psychology that have developed at the borderline of medicine and psychology. In order to understand the reasons it is first necessary to consider the special characteristics of cancer, especially from the point of view of the common person in general and of patients in particular.

What Do Patients Know in General About Cancer?

In order to understand the approach, decisions, and behavior of patients, it is important to learn about what they think or assume about cancer. Cancer is a prominent theme in the media and is often discussed by people in different social occasions. Information about cancer is shared quite freely precisely because it is a scary subject and getting information may provide some sense of mastery or protection.

What do patients usually know about cancer? Here is a list of some of the most salient and common characteristics of cancer mentioned by patients [1].

Difficulty Many of the beliefs and assumptions about cancer focus on difficulty. Majority if not all people know that cancer is a very difficult disease, in all respects and for every person. There is a kind of belief that even though the disease may subside or respond well to some treatment, it still deserves to be called “difficult.” Notably, even though there are other difficult diseases, the reputation of cancer is relatively worse than that of the others. The mere name of the disease is already indicative of its problematic character. Whereas diseases are mostly named after the main affected organ (e.g., headache), major symptom (e.g., whooping cough), or responsible agent (e.g., typhoid named after *Salmonella Typhi*), cancer is named after an animal that causes harm but is not the cause of cancer. Notably the word “cancer” has turned into a metaphor for a malicious agent that penetrates insidiously some bigger system causing harm and disorder [2].

Prevalence A second most salient aspect of information about cancer is its prevalence. Most people know that it is a highly prevalent disease. No one is immune: young children, teenagers, young adults, midlife adults, and the elderly – anyone can get cancer. Almost every person knows someone in the family or circle of acquaintances or neighborhood or from the media who is a cancer patient or died from cancer. Many people have had personal contact with a cancer patient. These personal experiences contribute to the feeling or illusion of many people that cancer is everywhere. Experiments in cognitive psychology have shown that the evaluation of the frequency of cancer may be subject to at least two so-called cognitive biases. One is known by the name “availability heuristic,” and it consists in the tendency to overestimate information that is easy to recall. The other is the “confirmation bias” which is the tendency to seek information that confirms and prioritizes information and conclusions that one already has.

Indeed, it is often difficult to pinpoint exactly the frequency or incidence of cancer, but it is evident for everyone who tries to get hold of the numbers that the incidence runs in the millions – millions of new cases, millions of death cases, and millions of survivors. But all these numbers boil down to a frightening mass of cancer events. Indeed, the numbers are somewhat confusing for anyone who tries to understand the situation. On the one hand the declaration is that the incidence of cancer does not increase, but on the other hand the news proclaim a higher number of projected cancer cases reflecting presumably better or finer diagnosis and probably an increase of certain types of cancer. Hence, the impression one may get is that not only is cancer a highly prevalent disease, but its incidence seems to be on the increase, and the age of its occurrence tends to get lower. Patients often mention the fact that a disease such as breast cancer that in former generations was known to be a disease of elderly or mostly postmenopausal women appears increasingly in young women, even as young as 30 years old. Patients often hear in the media about the discussions concerning lowering of the age of mandatory breast screening for women. They also refer often to information about breast cancer occurring in men, which creates the impression that the disease is spreading. Similarly, screening for colorectal cancer is increasingly undertaken as a standard measure for young men and women, such as those enlisting for the army.

Dangerous Further, most patients know that cancer is a very dangerous disease. In regard to cancer, danger means most often death. Indeed, death is the first association that patients have when they or someone close to them gets the diagnosis of cancer. Although there are undoubtedly many other fatal diseases, the connotation of cancer as a mortal or fatal disease is superior and highly dominant. Actually, it seems that cardiological diseases cause more deaths than all forms of cancer together [3]. Nevertheless, cancer is more closely reminiscent of death than heart diseases. This belief is further nurtured by the common publications about cancer statistics. Almost every publication about cancer statistics includes not only the number of cancer patients at a given time but also the number of deaths during that period as well as the number of cancer survivors, whereby even the mere use of the word survivor clearly denotes someone who has been close to death and somehow escaped that fate.

The dangerous character of cancer is enhanced especially because of the treatments for cancer which are notoriously known to be both difficult and not always useful. Cancer is known to be one of the most ancient diseases and yet does not have any reliable treatment. The short remark about a case of cancer found in an old Egyptian papyrus from the second millennium B.C. “there is no treatment” still applies in the view of many patients.

Chronic Disease When a patient gets the diagnosis of cancer, it is evident to him or her that if the verdict is not for death, then “this is for life,” namely, there is no recovery. Cancer is conceived as a one-way disease: once you are in it, there is no way out. The diagnosis of cancer stays forever. Patients often remark about the extraordinary situation of staying bound to the label, or rather the stigma of cancer forever, for as long as one lives. One often hears patients complaining about cancer as a set of unbreakable handcuffs placed on a person forever. The nagging question is, Why is it that one can be released from any disease, ranging from heart disease to syphilis, but not from cancer?

Elusiveness Elusiveness is one of the most salient negative aspects of cancer that render it difficult to deal with. All too often it turns out that the cancer has been in the patient’s body for a long time prior to its detection by accident, in the course of standard diagnostic procedures or on the basis of manifest symptoms. Furthermore, when it is finally detected, it may indeed be too late for full recovery or even for treatment. These facts are very scary because they give the patient the feeling that the cancer is hiding somewhere in the body, lurking in the darkness, as a kind of thief or some other evil creature that may leap out of nowhere unexpectedly with full force. Many patients tend to describe cancer as a hidden enemy which may be anywhere and everywhere without being detected. How can one fight a powerful enemy that resides in oneself without producing any signs of his or her existence? This conception of cancer is surprising because actually the same claims can be made about other diseases, including cardiological diseases, celiac disease, or multiple sclerosis, that develop slowly in the body over years without producing any specific symptoms that could lead to their detection on time. Diseases of this kind resemble cancer also in that for a long time they may produce fuzzy nonspecific symptoms which may be confusing and render it hard to identify the underlying cause. However, it is mainly cancer that gets the bad reputation of being elusive and non-detectable.

Moreover, the diagnosis of cancer is far from straightforward. It is often based on a series of medical tests which may take time to decipher. Sometimes even after some time, the diagnosis is not always conclusive, and different experts may have different opinions about it. Further, there are over 100 different cancers, and some of them have distinct pathologies and manifestations. Actually, patients are aware of the more recent conceptualization of cancer as a family of diseases.

And then, there is the issue of metastases about which every patient knows. This aspect of cancer is highly disconcerting. Metastases may mean two things to a regular patient: one is that although the main tumor or nodule of cancer has been

overcome by treatment, there may still be components of the cancer in the body that may be too elusive or tiny for detection at that time. The other implication is that one may never know whether one is healthy or free of cancer or not. This is particularly upsetting for patients because upon diagnosis, they have learned that for months or even years, the cancer may have been developing in their body without them being aware of this in any way.

A similar situation exists in regard to biomarkers. Biomarkers are considered by physicians and patients as indicators of malignancy but not always, that is, not in regard to every cancer and not in regard to every patient and not in regard to any phase of the disease. Thus, if the patient gets information about biomarkers that clearly supports the existence of malignancy, there is some clarity in the meaning of that information. If, however, there is no indication for biomarkers, the patient still remains in limbo. The nagging question “Do I have cancer or am I healthy” persists without answer.

Physical Suffering The conception of many patients concerning cancer and its treatments may be summarized under the heading of suffering. Many patients have recollection of their relatives, sometimes parents, in former generations or other acquaintances who have gone through the process and have complained of a lot of physical suffering. This may be one source of information for most patients. For many people cancer is related to pain, harm to the body, loss of body organs or limbs due to surgery, physical deformation, fatigue, physical wasting, loss of weight, swelling of body or body parts, loss of appetite, nausea, and weakness.

Psychological Suffering Many patients may be more scared of the psychological suffering than of the physical suffering they envisage for cancer. Patients expect that cancer would bring about many changes in their routine and daily life and that they would not be able to do most of the things they are used to doing and that bring them joy and make them happy. They are doubtful about the possibility of going on with their work, and some of them are conflicted about whether they would like to go on working. At least some may have financial worries due to difficulties with work and treatment expenses. They also expect changes in their social life, mainly because they assume that their friends and acquaintances may not like to continue the relationship with them or may withdraw because of the stigma connected with cancer. They know this about others because maybe they themselves have experienced similar emotions when friends or acquaintance got cancer. They felt then they did not want to have anything to do with the cancer. Hence, they also know that it is difficult to talk with others about one’s cancer. Doing so may cause others to pity you or withdraw. The patients assume that getting cancer means sadness and loneliness.

Patients also know that no one stays the same after getting cancer. There are changes in role at home and at work, there is loss of mastery and independence, and there may be a need for help from others which may impact one’s self image and self-confidence.