New Challenges in Communication with Cancer Patients

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Preface

The basis of any human coexistence is communication. Communication is also the basis of every therapeutic action. The more severe and threatening the illness is, the more important the communicative interaction between the affected persons … and the medical professional or team.

So write Drs. Klocker-Kaiser and Klocker in their chapter of this book. Their words go to the root of the book's subject. Communication between cancer patient and oncology professional is essential to the achievement of their common goal—bringing about the greatest length and quality of life for the patient. Such communication is a complex, evolving subject.

Communication with the Cancer Patient: Information and Truth (Annals of the New York Academy of Sciences, Vol. 809, Antonella Surbone and Matjaž Zwitter, eds.) was published in 1997 and offered a representative view of the field at that time. Since then much has changed in the content, methods, and circumstances of communication between cancer patients and their doctors—the growth of modern information technologies, to name just one. The editors believe the time is ripe to present a new picture of the field in its various aspects. Toward that end we have assembled 42 chapters by professionals in the field practicing in 22 countries throughout the world. No attempt has been made to be systematic or complete; the authors discuss a large range of issues of current interest and importance and offer a wealth of ideas for what is needed to improve communication between cancer patients and physicians.

Assembling this book has been an inspiring, rewarding task, but not an easy one. Oncologists tend to be very busy people, and writing tends to demand substantial time and effort. We are grateful to the authors who have been willing and able to offer us and you, the reader, their knowledge, experience, and wisdom; we hope their work will inspire you to communicate more effectively with your patients and to join the continuing discussion of this important topic.

We wish to thank Ms. Laura Walsh and Ms. Rachel Corsini, of Springer Science+Business Media, for their invaluable assistance in assembling and publishing this book.

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Introduction
Communication: Back to the Human Side of Medicine

Diagnostics, treatment, and communication are the three pillars of oncology. None of them can stand alone; even two of them are not enough, just as a table cannot stand on two legs. By definition, if all three are indispensable, no one is more important than the others. If one fails, the other two collapse, and the game is over.

None of us can imagine oncology without a laboratory. No one should ever say "I can't do anything for this patient," since our help is most needed precisely at the moment when the standard treatment guidelines are no longer enough to support our decisions. And no one should approach a cancer patient without a sincere, honest, humble desire to knock on the doors of a new world, of a new, unique person.

Until 100 years ago, medicine was an art, very close to philosophy, theology, and the other humanities. In the twentieth century, modern science came on the scene and, somehow, kidnapped medicine. The unbelievable progress of biology, natural sciences, and technology shifted our attention to precise diagnostics, often based on our increasingly deeper understanding of genetics, and to remarkable new possibilities of effective cancer treatment. By the end of the century, however, a second kidnapping of medicine came about more silently, without Nobel Prize laureates: this time money was responsible. Not all of us are fully aware of the dominant role of pharmaceutical companies, which are intruding into all our activities, including everyday medical decisions, medical research, medical conferences and journals, teaching, regulatory bodies, medical societies, the formulation of national and international guidelines, and the distribution of financial resources.

The time has come for medicine to reclaim its roots and its place among the humanistic sciences—fully scientific and fully humanistic. This is not a nostalgic desire for the "good old days," since none of us would wish for our cancer patients to be deprived of today's increasing chances of being cured or of living with cancer as a chronic long-term illness. Rather, it is becoming obvious that the spiral of progress, with its technical and biological discoveries and its unlimited self-confidence, is leaving aside an essential element of cure and care: the fragility and strength of the human soul. Medicine without a soul is a table on two legs, bound to collapse.

To restore the human dimension of medicine, communication is indispensable. This is even more true for oncology, a discipline that inevitably deals with patients harboring a serious, often incurable, illness pervaded with existential, physical, and psychosocial suffering.

This book offers a nonsystematic approach to the wide spectrum of opinions, ideas, and experiences around one central issue: bringing patient and physician together and helping them both cope with the illness in the most appropriate way. In this introductory chapter, we will briefly review the five sections of the book, which we call the five dimensions of communication:

- The illness: discovering its truths
- The patient and the family
- The physician
- The cultural and social context
- The contribution and interference of modern information technologies

The book's chapters are grouped in correspondingly titled sections and are presented in the order in which they are referred to here.

The Illness: Discovering Its Truths

Surbone
Aggarwal and Rowe
Schapira
Al-Amri
Stiefel and Krenz
Grassi, Caruso, and Nanni
Abrams
Norris, Walseman, and Puchalski
Thombre and Sherman

In spite of medical progress, talking about cancer is still, in its essence, talking about our own mortality. And when we speak about mortality we speak about values of life: death and mortality are what make our lives valuable. When we think about the end of life (or, some will say, the end of this life), we realize why we wish to live. Talking about life and death is talking about values. Once values have been introduced, truth is no longer a static object. Physician and patient discover truth as a unique meeting point of their values.

We are never really prepared for the shock of a diagnosis of cancer: denial, anxiety, depression, and fear are normal reactions. On the physician's side, trust and honesty are essential to building a sincere relationship with the patient. Quite often, the message of bad news is not a single event; rather, the sequence of fear, bad news, hope, and then bad news again may be a patient's and physician's companion from diagnosis until the end. As we do not live in isolation, the waves of concern, depression,

hope, and irrational thoughts spread to family, friends, and even to unknown people or to self-proclaimed healers. Following the principles of integrative medicine, a physician restores the central position of the patient and assists him or her in resuming responsible decisions.

Yet, the earthquake in our soul also has a positive side. The experience of serious disease brings forward spiritual issues, and cancer can, indeed, turn out to be one of the most enriching experiences in life.

The Patient and the Family

Baider
Parikh, Prabhash, Bhattacharyya, and Ranade
Aljubran
Lascar, Alizade, and Diez
Balducci and Extermann
Husebø and Husebø
Biasco, Moroni, and De Panfilis
Carapetyan, Smith, and Muggia

Cancer does not affect a single individual, but also those around him or her. Virtually every text on communication with the cancer patient emphasizes the importance of establishing a sincere relationship with the patient's family, friends, and community. Most often, the family supports the patient, and experiencing the threat of a serious disease brings family members closer and helps reestablish broken relationships. Yet, the opposite reaction is not rare: family members may simply be unable to cope with such a stressful situation. In many cultures, the family tries to protect their sick relative by blocking all direct communication and insisting on withholding the truth about the malignant nature of their illness.

There is no doubt that cancer in a child affects the whole family. While parents are always involved, siblings also feel the shock of a new, extremely stressful situation. The emotional burden upon the siblings is often ignored: the "go and play" attitude is clearly inappropriate, as it leaves them hurt by their fears and without attention. Sincere talk not only to parents but also to a child with cancer and his or her siblings can remove much of the tension. Last, but not least, pediatric oncologists themselves need support for their exhaustive work and most often they get it from sincere communication with their little patients.

In this section on patients and family, we include also the other extreme: elderly patients and patients requiring palliative and end-of-life care. Here often it is not the presence, but the *absence,* of family that must be considered. Communication with elderly cancer patients and with those approaching the end of their life is all too often a pale substitute for what these patients really wish for and need: the caring presence of a close family member. Drugs can relieve pain, constipation, or insomnia; but no drug can relieve the feeling of abandonment. A sincere human relationship

with a physician can restore dignity. And it must not be forgotten that a warm "thank you and good-bye" from a dying patient also has a powerful healing power for the oncologist and staff members of a palliative or geriatric unit.

The diagnosis of a hereditary cancer brings distinct issues into communication with a cancer patient. Even for the most individualistic patient, such cancer ceases to be only his or her own problem and becomes an issue that directly concerns other members of the family. For young patients, a diagnosis of hereditary cancer also opens questions of family planning, including the option of preimplantation genetic screening: genetic counseling thus requires special communication skills.

The Oncology Professional

Die Trill
Klocker-Kaiser and Klocker
Annunziata and Muzzatti
Lowenstein
Brook
Dikici, Yaris, and Artiran Igde
Baile
Travado
Fujimori, Shirai, and Uchitomi

The great majority of physicians of any specialty occasionally see, diagnose, or treat a patient with cancer. For some physicians, however, oncology is their only discipline.

We believe that experience in communication is among the most important reasons why cancer should be treated by oncologists. For physicians of other specialties, a cancer patient may be an unusual challenge or even an additional burden; oncologists, by contrast, choose to invest all their knowledge and empathy for the benefit of cancer patients. Good communication includes sharing knowledge as well as emotions, and listening to patients' narratives, by giving priority to subtle nuances rather than binary thinking. Careful listening to patients' complaints can also protect patient and physician from medical errors.

While stressing the importance of trained oncologists in cancer treatment, we do not underestimate the role of physicians of other specialties, who are indispensable in a multidisciplinary approach to cancer. A special place goes to practitioners of family medicine, who make invaluable contributions at both ends of the journey of most cancer patients—in finding the first suspicion of malignancy and in palliative treatment in the home setting. Hence, proper education of and support to family physicians are of utmost importance.

Can communication with the cancer patient be taught, or is it a talent that some physicians simply possess or acquire through experience? It seems that both answers are correct. Traditionally, there was no formal training in communication,

a situation resulting in a wide spectrum of attitudes, ranging from physicians with deep empathy and excellent communication skills to others who seem totally unaware of the communication needs of their patients. However, there is now no doubt that inappropriate practices can be changed and that communication can be improved by proper teaching of communication skills.

The Cultural and Social Context

Cohen
Dolbeault and Brédart
Pavlovsky, Bertolino, Patxot, and Pavlovsky
Kagawa-Singer
Butow, Tattersall, Clayton, and Goldstein
Güven
Montazeri
Mehic
Schwartsmann and Brunetto
Demin and Gamaley
Ndlovu

The dependence of communication on cultural factors is increasingly being recognized and studied. The influence of culture on perceptions, beliefs, and reactions to a severe illness such as cancer is especially evident when one compares attitudes and practices in different countries where health care systems are also different. As most Western countries are becoming increasingly multiethnic and multicultural, cross-cultural medical encounters are becoming more frequent; they need to be approached with cultural competence: culturally sensitive communication with patients and families is necessary when patients and oncology professionals do not share the same culture. We are referring not only to differences in ethnicity, nationality, language, and religion, but also to such factors as gender, age, sexual orientation, disability, education, health literacy, and socioeconomic status.

As any clinical encounter is an encounter of different fellow human beings, oncology professionals should always practice sensitivity, humility, and curiosity in carefully exploring the patient's cultural and individual beliefs, preferences, and priorities. Listening and understanding comes as the first step of communication and is at its core, followed by a continuous sensitive reassessment of the patient's wishes, preferences, and needs, which evolve during the course of the illness. The oncologist should establish a trusting relationship with the patient and discuss with him or her the most appropriate plan of care, from both the medical and the patient's cultural perspectives. Psychosocial assistance is essential both in communicating the diagnosis and in formulating a realistic treatment plan. Good communication is of utmost importance for treatment compliance. Cultural sensitivity

and competence comprise a set of knowledge, skills, and professional values that can and should be taught.

In many parts of the world and within some communities in multicultural countries, physicians' paternalism has deep and strong roots, to the extent that open discussion with a cancer patient is considered inappropriate and harmful to the patient. Despite a wealth of Western empiric studies showing that better-informed patients contribute more actively to their care plans and receive higher quality of care at medical and psychosocial levels, in many countries patients are still kept unaware of their cancer diagnosis and prognosis.

Economic inequalities and their influence upon medical decisions are rarely discussed, even in many democratic societies. Yet, low socioeconomic status has been confirmed as an independent unfavorable predictor of cancer survival. The difficult balance between the optimal treatment and the treatment that is realistically available is achieved largely through open communication between oncologists and their patients.

African countries appear to face a special blend of deeply rooted traditional beliefs regarding the origins and treatment of diseases, economic deprivation, a high prevalence of HIV infection, and the priority of the family over the individual in making decisions. In such a setting and until comprehensive cancer programs become available, communication with cancer patients is often limited to basic help and symptomatic relief.

The Contribution and Interference of Modern Information Technologies

Vasconcellos-Silva
Rajer
Zakotnik
Zhuang and Chou
Zwitter

The extent to which modern information technologies influence all our relations is enormous and rapidly growing. The information obtained through the Internet, albeit not always reliable, has already replaced in large part the direct flow of information from physician to patient. We as oncologists have no choice other than to be knowledgeable and proactive with regard to virtual medical information. Ignoring the importance of virtual global communication media would give even more power to those who see medicine exclusively as a profitable enterprise.

Even before the Internet, printed educational material was used to disseminate information about specific cancers, their early symptoms, diagnostics, and treatment. While this printed material can, indeed, spare some physician's time, it should not become a substitute for bidirectional talk with the patient.

The global presence of the Internet and related communication networks has dramatically changed the level of information available to patients. This, in turn, has generated a strong pressure upon health professionals and policy makers responsible for resource allocation and the organization of medical care. In China, until recently considered a developing country, most patients from urban areas consult the Internet even prior to their first visit to an oncologist.

Finally, we come to the question of communication in clinical research. As an activity directed to improving the efficacy of our treatments, research is not only ethically justified but, indeed, indispensable. Clinical research has brought significant progress in virtually all fields of oncology. Yet, ethical problems remain, and most of them are connected to communication: information for patients aims at protecting the sponsor, rather than informing the patient in support of his or her free decision-making. If we are sincere in our words about patients as partners in research, then we should offer them information that is accurate, simple, and understandable to each patient.

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Part II The Patient and the Family

Part III The Physician

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Part I
The Ilness: Discovering Its Truth

Chapter 1
From Truth Telling to Truth in the Making: A Paradigm Shift in Communication with Cancer Patients

Antonella Surbone

Abstract Direct observation shows how traditional narrow biomedical conceptions of truth in medicine, coupled with increasing technological sophistication and the consequent fragmentation of care practiced under major economic constraints, run parallel to a loss of humanism and of satisfaction for both partners in the patient–doctor relationship. A new conceptualization of truth in medicine, and of communication about it, is needed to restore the integrity of clinical practice, medical education, training, and health care policy. Multiple truths are at stake in clinical medicine, different and yet interrelated. These truths are shared by both partners within the patient–doctor relationship, rather than being simply discovered or imposed by health professionals. A nuanced understanding of the truths at stake in clinical medicine as essentially relational, dynamic, provisional, and situated gives raise to a paradigm shift from truth telling to truth making. This can not only improve communication between patients and their oncologists, but also affect perceptions, attitudes, and practices of education and training, as well as public perceptions of emerging aspects of cancer care and policy making with regard to minority cancer patients and survivors, elderly cancer patients, or mutation carriers.

Keywords Truth telling • Truth making • Patient-doctor relationship • Asymmetry • Trust

Introduction

My reflections on communication in oncology stem from over 20 years of practice of medical oncology, including designing, conducting, and reporting clinical trials and counseling underprivileged and minority women who undergo genetic testing

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for breast and ovarian cancer predisposition; as well as from my scholarly work in the philosophy of medicine and the ethical implications of clinical oncology. These have taught me that the essence of being an oncologist goes far beyond the increasingly possible therapeutic successes of cancer therapies and that it lies in the human connection between us and our patients [1–3]. This connection is built and maintained through communication with our patients—a bidirectional process that poses increasing challenges in today's multicultural, highly technological, and globalized world, where we need to disclose painful truths without destroying hope or discuss uncertainty without diminishing our patients' trust in our full commitment to care and be there for them even when cure is no longer possible [4–6].

The many challenges of communication with cancer patients are addressed in detail elsewhere in this book. My contribution aims rather at clarifying what is the subject of our communication with cancer patients: not a static, predetermined truth known only to us oncologists and waiting to be disclosed to our patients, but rather a "truth in the making," which emerges over time within and from each individual patient–doctor relationship, under the influence of many contextual, internal, and external factors [7].

While clinical medicine and oncology deal with many truths, the cancer patient and the oncologist engage in a reciprocal relationship in search for the unique truth of the particular patient's illness, with the specific therapeutic goal of curing the illness or alleviating its symptoms [7]. The notion of illness, in contrast to the more restrictive notion of disease, is a complex, multilayered one, encompassing objective, subjective, and intersubjective elements, including sociocultural ones [8–14]. Various methods of inquiry into the truth and various criteria of truth contribute to understanding the patient's cancer. The truth about its objective dimension may seem, at first glance, to be only the sum of pathologic, molecular, and genetic changes. These, however, occur in an embodied living subject, who experiences the symptoms and signs of cancer in a given context and manifests the discomfort or suffering associated with his or her illness according to socioculturally determined and accepted expressive means [4, 7, 15, 16]. Understanding and applying these concepts lead to a holistic view of illness and of cancer care that are necessarily based on open, effective communication.

Despite the increasingly recognized role of subjectivity and intersubjectivity, and of uncertainty, ambiguity, and vagueness in the contemporary philosophy of science, the strict biomedical view of disease, based and focused on objective quantifiable data obtained generally by ever-improving technological means, still pervades Western medicine and medical training [17–19]. When the subjective and intersubjective elements of illness are not taken into proper account, the illness is reified. Reification is a process that occurs when an object is posited as being given, rather than the result of human actions and interactions [20, 21]. Reification of an illness means that its truth is reduced to that of an external static object awaiting experts' unilateral discovery, description, and truth telling [4]. In such a perspective, the physician becomes increasingly dominant, while the patient is silenced.

On the contrary, the many interrelated truths of the patient's cancer are known by both the patient and the doctor together, albeit from different perspectives.

Objective and subjective dimensions give rise to the reality of a person's illness within the context of the patient–doctor relationship, in which the anonymous, ambiguous suffering of the patient is open to the rational scrutiny of the doctor, who interprets it and transposes it to a level of rationality and objectivity, where it can be more easily managed [22]. Such a process is the result of interactive, selective presentation and interpretation of multiple stories and multiple data by both parties [23].

The increased emphasis on personal self-governance in most Western countries is mirrored in the current model of the patient–doctor relationship, which includes the doctors' moral obligation to respect and foster their patients' autonomy and to develop equal partnerships with them, first and foremost through the practice of disclosure and informed consent [24]. The autonomy model is in sharp contradistinction to the formerly dominant paternalistic model of charismatic physicians who, at their discretion, maintain all power, including that of withholding the truth. Truth telling, however, has often been reduced to a matter of providing information, rather than sharing a truth in the making that emerges from the relationship itself [4].

The patient–doctor relationship is inherently asymmetrical at the existential, social, and epistemic levels. The ill person, by virtue of the illness, is in a "uniquely dependent state" [25]. Vulnerability limits the patient's autonomy and introduces an element of dependency on the physician, as the patient begins to relate the "truth" of his or her symptoms and the doctor elaborates and pronounces another "truth" in terms of diagnosis, prognosis, and risks [22, 26]. A nuanced conceptualization of truth in medicine as relational, dynamic, and provisional that takes into consideration the asymmetrical nature of the patient–doctor relationship and the specific knowledge of each partner can lead to true communication and advance the cancer patient's autonomous participation in his or her treatment and care.

Sensitive and effective communication also contributes to changes in the practice of clinical oncology and might have a "bottom up" influence on healthcare policy, through larger-scale changes in public and professional perceptions and attitudes toward cancer patients and survivors. Oncologists often struggle to maintain their allegiance to the individual patient in the midst of impossible institutional demands, and yet have some freedom to create positive policy changes in day-to-day practice, strategizing with their patients to provide the maximum quality and quantity of care within financial constraints and institutional demands [7].

For a shift from truth telling to truth making to occur, it would be necessary to introduce in medical school curricula a dynamic, evolutionary concept of truth in clinical medicine and of the social, scientific, technological, and economic forces that shape clinical practice. The development in medical students and oncology fellows of an appreciation of the interpersonal, social, and ethical issues of power, control, authority, dominance, dependency. and responsibility in the patient–doctor relationship, with attention to the current situation and the foreseeable changes in future clinical practice—such as those due to the aging of the worldwide population or the developments of genetics—is key to laying the foundations for open, effective communication with all cancer patients [27–29].

Understanding the Dynamic, Relational Nature of Communication with Cancer Patients

Each patient–physician interaction is inherently dynamic and relational in nature, expressed in a series of steps and occasional epiphanies that lead to a shared understanding of the patient's illness, made of multiple, particular, provisional, and often partial truths that encompass different elements and levels. These truths are also of different kinds: medical, clinical, therapeutic, as well as scientific; existential, practical, and moral, as well as objective; in the first as well as the third person; and about diagnosis as well as prognosis and cure (or lack of cure). These disparate truths rarely blend harmoniously into a single truth. Rather, there always seems to be a persistent gap, an unbridgeable distance between the subjective and objective elements of the illness [7, 30].

There is also a distance between the cancer patient and the oncologist, which is not merely existential, but primarily epistemic, as the patient and the doctor learn and know different aspects of the patient's illness and its treatments. The patient knows by direct personal and singular corporeal experience, the physician by generalization and abstraction [4]. Not only are they two different knowing subjects making use of the different cognitive categories of subjectivity vs. objectivity, but the objects of their knowledge and their interests are different. It is in this gap that the truths about the patient's illness are "in the making" [7].

Truth in the Making: A Paradigm Shift in Communication with Cancer Patients

Viewing truth as in the making leads to a paradigm shift in the traditional conception of truth telling to, and communication with, cancer patients. The conceptual framework necessary to support this shift can be summarized as follows:

1. Illness consists of more-or-less objectively quantifiable data that are subjectively lived, intersubjectively interpreted, and socially constructed. By contrast, the objective dimension of the person's illness, generally referred to as the "disease," consists of measurable anatomical, physiological, biochemical, molecular, and genetic changes that are independent of the patient's will [19]. The changes that make up the disease occur in a specific human being, where body, psyche, and mind are united as a whole. They impose a functional rigidity or limitation with respect to the homeostatic relationship of the person and its environment [31]. This rigidity results in a condition of discomfort and suffering of various kinds and degrees. The more-or-less ambiguous consciousness of this suffering constitutes the subjectively lived dimension of a person's illness [32].
2. The objective and subjective elements of each illness are interpreted within the context of the patient–doctor relationship, where the patient's experience of suffering is offered to the scrutiny and interpretation of another person—an expert, the