F. Stiefel (Ed.)

Communication in Cancer Care

With 6 Figures and 10 Tables
To Fabienne, Axelle and Léa
Cancer is often seen as precipitating an existential crisis; a crisis of spirit and an opportunity for meaning. This is true not only for the patient with cancer and his or her family and loved ones, but also, interestingly enough, for oncologists and cancer care providers. For the patient the challenges are dealing with fear and uncertainty, maintaining a balance between hope and despair, comprehending information and enacting shared decision making, living with choices, and, for too many, finding a way to accept death. For the family the challenges are equally daunting; finding a way to support their loved one and help them maintain hope, advocate on their behalf, help collect and integrate information. This must all be done while not allowing one’s own fear and depression to produce a state of isolation for the patient. For the oncologist and other cancer care providers the challenges are fierce as well; finding a way to impart information clearly, finding a way to empower patients in a shared decision making endeavor, finding a way to maintain hope and most importantly somehow finding a way to prevent technology and modern science from dehumanizing the doctor–patient relationship. What we are learning, from this new and rapidly evolving field of cancer communication research and training, is that good communication in cancer care can be a bridge to hope and healing.

Communication issues in cancer care begin even before a cancer diagnosis, in cancer prevention strategies, and extend to all phases of treatment, survivorship and end-of-life care. Communication in cancer care involves the patient and the family, as well as all the members of the cancer treatment team. Finally, communication in cancer care must address issues specific to patients of all ages, diverse cultures and lifestyles. Perhaps two of the most well-developed areas in communication in cancer care relate to shared decision-making research, and the effectiveness of communication skills training of cancer care providers. The field of communication research and training is thus quite broad and still in development, although much has been accomplished, as is illustrated in this textbook.

This text, Communication in Cancer Care edited by F. Stiefel, represents one of the most comprehensive as well as clinically relevant edited volumes on the subject of communication in cancer care to appear to date. Professor Stiefel has enlisted international experts in a very broad range of cancer communication areas including: cancer prevention, genetic counseling, all phases of cancer treatment, palliative care, communication with children, families, culturally specific communications, interdisciplinary communication and communication skills training. The table of contents contains some interesting juxtapositions of chapters including a chapter on “Informing About Diagnosis, Relapse and Progression of Disease – Communication with the Terminally Ill Cancer Patient” by Drs. Stiefel and Razavi, followed by a chapter on “Maintaining Hope: Communication in Palliative Care” by Dr. Mary Lloyd Williams.

The contributors include an international array of experts in cancer communication and psycho-oncology. Contributors represent experts from Switzerland, Belgium, England, France, Germany, The Netherlands and Italy. This international perspective is a testament not only to the relevance of cancer communication throughout all cultures, but also to the growing importance...
and interest of the oncology and psycho-oncology communities in developing research and training in communication in cancer care. This also represents the recognition that the delivery of optimal cancer care cannot take place without skillful, effective, and compassionate communication taking place.

As we face the future of cancer care, it is clear that we are in store for more advances in technology, diagnostics and treatment that have the potential to create an even greater detachment between the patient and the cancer care provider. The potential for further de-humanizing or de-personalizing the practice of oncology is readily evident. Thus the importance of communication in cancer care grows greater and more critically relevant with every passing moment. This text represents a major advance for the field of communication in cancer care, and its publication is timely and well received.

On a personal note, I am particularly gratified that Prof. Stiefel has given me the opportunity to write a few words of introduction to the text he so skillfully created and edited. Our professional relationship and personal friendship dates back almost 20 years, to the period of time that Prof. Stiefel and I conducted our first research studies together at Memorial Sloan-Kettering Cancer Center. It gives me great pleasure to congratulate him on this extraordinary contribution to the fields of Psycho-oncology and Cancer Communication.

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Summary

In this chapter the “communication compass” is introduced. It defines the key elements of communication and provides a language with which to communicate about communication in cancer care. The communication compass consists of two axes. One axis defines the associated perspectives of the clinician and the patient, the other axis the content of information and emotional experience.

“Two lovers sat on a park bench with their bodies touching each other, holding hands in the moonlight. There was silence between them. So profound was their love for each other, they needed no words to express it.” (Samuel Johnson)

Sometimes communication just flows. There are these special moments, as fleeting as they are intense. Often communication is stuck. It is as if we speak another language and never manage to understand one another. The lovers on the park bench need no words to express what they feel, neither do they need words to speak about communication. Where communication gets stuck, we need a suitable language to speak about communication.

Professional communication cannot be learned from a cookbook. Most of all it implies a readiness to communicate, which means openness to the other. The old adage that it is impossible not to communicate is only true if no criterion of quality is applied. As soon as some mutual understanding is implied in the definition of communication, the fact that it is at all possible to communicate becomes a miracle.

Since there is an important gap between theory and practice, we created a tool that aims to bridge that gap. We call it the communication compass. It does not propose a model of “ideal communication,” but provides a language with which to examine and analyze specific situations and to determine what the pitfalls and possibilities are. It is useful as a tool for identifying communicational difficulties in daily clinical practice and it can serve as a model for training basic communication skills (see Fig. 1).

1.1 Communication Compass

1.1.1 Perspectives

“You’re lucky,” the oncologist tells his patient with breast cancer. “Your tumor seems to respond well to the hormone therapy. And we still have a lot more possibilities in the future.” “Does that mean that I am going to be cured after all?” the woman asks. After the consultation the doctor sighs: “How is it possible after all the explanations I have given, that the patient still has not understood that this therapy does not have a curative intent?”

The first axis in the compass is the axis of perspectives. Who is lucky in the above-mentioned example? It is the doctor who is lucky, because his therapy is working. From the perspective of the patient, being lucky has a completely different meaning. She does not know the doctor’s other patients. For her, being lucky means to be free of cancer. That is how she understands her doctor’s statement. Doctor and patient look at the same situation from a completely different perspective.
Our scientific mind is not familiar with thinking in perspectives. On the contrary, the essence of science is to approach an objective point of view, independent from perspectives. The weight of an object is measured independently of the one who has to carry it. What is heavy for one may be light for another, but expressed in kilograms it is the same for both. In communication, we have little use for this objectivity. Reality is different from a different perspective. Both perspectives are equally important. Perspectives are the raw material of communication.

The first point in communication is the recognition of the perspective of the other. The key question is: what does the world look like through the eyes of my patient? The problem is that we only have access to our own perspective. We are not wired to our patient. We will never know what it is to be him or her. The question remains open, and has to be put over and over again without ever getting a final answer. In Zen there is a saying that when you have not seen someone for more than two minutes, you no longer know him.

The miracle of communication is that without having direct access to the other’s perspective, we can have a feeling of mutual understanding. Communication is based on the recognition of two perspectives. That does not mean it always implies agreement. We can achieve mutual understanding and still realize that our experience of the world, our values and beliefs are completely different.

An important caveat here is not to lose sight of your own perspective. This sometimes happens when, with a lot of goodwill, we try to empathize with the perspective of the other and lose ourselves in that perspective, temporarily forgetting our own view. Our patients do not benefit from our absence in the communication process. When either one perspective gets lost, mutual understanding is lost.

1.1.2 Information and Experience

Case 1
- Jansen Maria, 34 years old, married with two children.
- Breast cancer, T1 N3 Mx
- R/radiotherapy

Case 2
- It hasn’t quite sunk in. She functions as if intoxicated. Every now and then the harsh reality comes through. Cancer! What about the children now? And my husband? She freezes. It cannot be, it cannot be true.

Both cases above refer to the same patient, at the same moment, but the two descriptions are in no way similar. “Case 1” contains pure information about the patient’s medical status. “Case 2” describes her experience. The difference between information and experience is presented here in

![Communication compass](image)
an extreme way. In communication, both aspects are present at the same time. Therefore, the second axis of the communication compass consists of “information” and “experience.” The two aspects of communication must not be confused.

The head nurse notifies the doctor that Mr. Hermans has a request for euthanasia. When the doctor questions him, he is surprised. In a moment of great distress he has exclaimed, “Please let me die, I can stand this no longer.” He had never meant this to be taken literally. He does not want to die. Certainly not now, that his new pain medication starts to work.

The typical mistake is that an expression of the patient’s ongoing experience (despair) is taken as information (a request for euthanasia). Information and experience are not interchangeable. A request for information should be answered with information, and an expression of experience is to be answered by acknowledging the patient’s experience.

Mr. Jones is a retired physician. He is treated for prostate cancer. After his last consultation with the urologist he feels upset. The urologist told him, “According to the statistics of prostate cancer, you still have 13 years to live. According to the statistics for the healthy population you have, 15 years to live.”

However correct and reassuring the information may seem to be, it upsets the patient because it ignores his experience of fear. It is erroneous to assume that information counteracts fear. Experience needs recognition. That does not always imply more time. It would have been entirely different for the patient if the doctor had started his sentence with “I understand you are afraid,” followed by exactly the same information.

“Doctor, I want to know, is it cancer?” “You don’t need to be worried so much. Medicine nowadays has a lot more means than it used to have to cure your condition.”

The opposite is a pitfall as well. When asked for information, one should not try to escape delivering bad news by focusing on the emotional experience. Only correct information about diagnosis and possible treatment is the adequate response to this question.

1.1.3 Information

Giving information is challenging. Often we think we have done our job when we have explained it all to the patient, only to be disappointed that he did not understand our explanation. The word “giving” in “giving information” is misleading. When I give you my watch, you have it and I have lost it. When I give you information I do not lose anything, and there is no guarantee that you have it. Information is not something you can “give.”

With regard to information, the clinician is in the role of the expert. That is what he has studied for. The patient (usually) does not have that background. The consequence is that the patient receives the information in a very different frame of reference.

It is important to find out what the patient’s frame of reference is. How does he perceive his situation? What does he know and how does he understand what he knows? Effective transfer of information starts with probing where the patient is. Assuming that the patient automatically understands the information you give him is a very effective recipe for misunderstanding and frustration (on both sides).

“Let’s have a look at the results. The blood tests seem OK and on the scan nothing has changed. Only the result of the pathology test is problematic; it says you have a high grade B-cell lymphoma.”

“So I don’t have cancer after all?”

It is important to present information in a clear, and for the patient understandable, language. Do not, as illustrated above, start with the less important and seemingly reassuring. Do not try to make it feel better than it is. Bad news is inherently bad. Start with what is essential and only then move into details, if the patient still understands you. Then, check how the patient has understood your message. Especially in the case of bad news, the patient may get lost in his experience and no longer hear what you are saying. Often it is necessary to repeat information time after time. Since you never know how the other receives the information, always check.