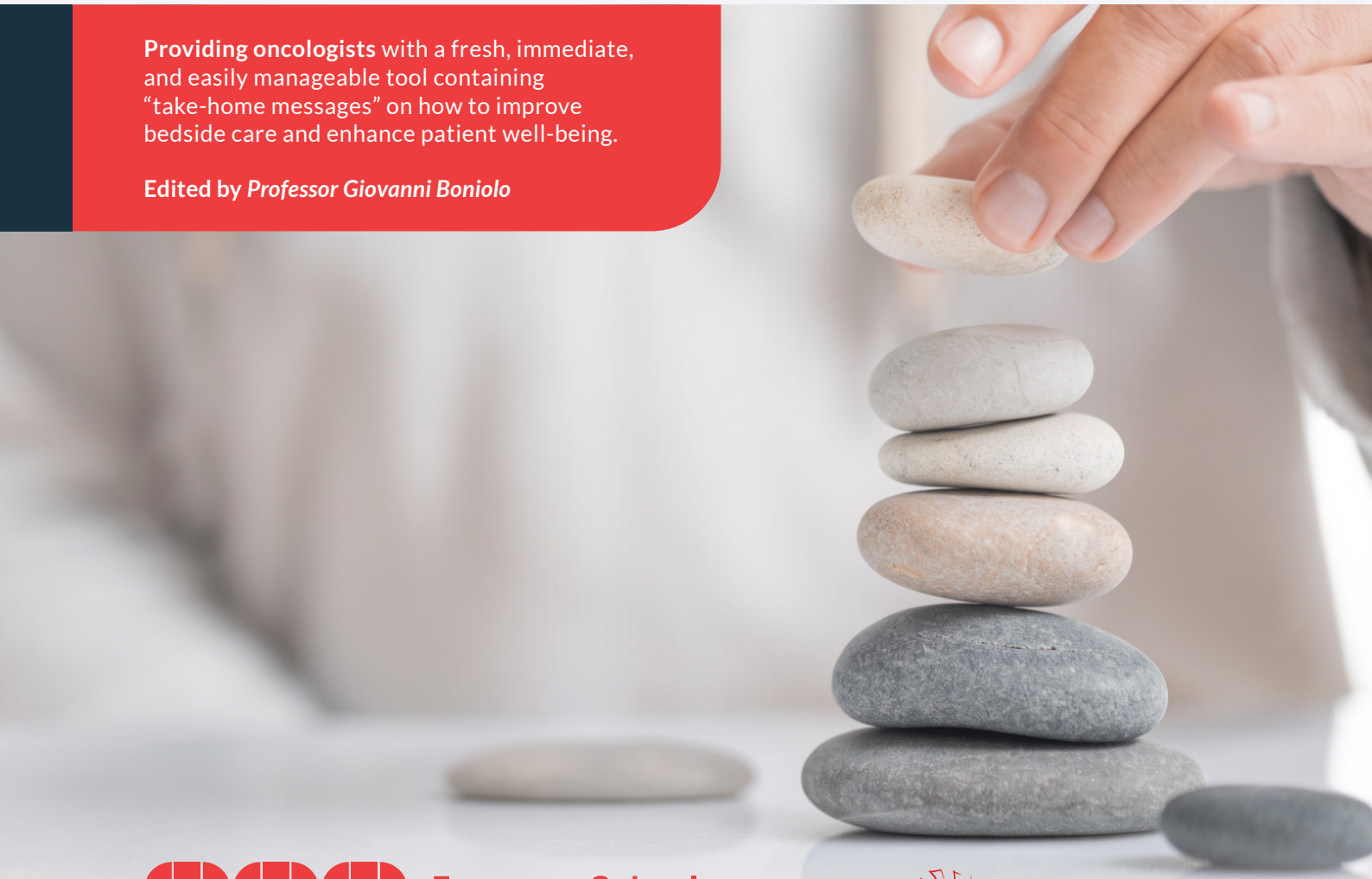
Learning Oncohumanities to Care

For a human-centred oncology

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Providing oncologists with a fresh, immediate, and easily manageable tool containing "take-home messages" on how to improve bedside care and enhance patient well-being.

Edited by ***Professor Giovanni Boniolo***



European School of Oncology

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Learning Oncohumanities to Care — for a human-centred oncology
edited by Giovanni Boniolo

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INTRODUCTION

Oncohumanities: From Disease-Centred Medicine to Human-Centred Oncology

Giovanni Boniolo

Cancer remains one of the greatest and most complex challenges confronting global health. As the second leading cause of death worldwide, it imposes an immense burden on individuals, families, healthcare systems, and societies, while exposing persistent inequalities in access to prevention, early diagnosis, treatment, survivorship, and palliative care. At the same time, oncology has undergone an unprecedented scientific and technological transformation. Advances in molecular biology, immunotherapy, radiotherapy, genomic and post-genomic profiling, imaging technologies, predictive algorithms, artificial intelligence, digital decision-support systems, and increasingly personalised therapeutic strategies have profoundly reshaped every stage of cancer care.

These developments have significantly improved diagnosis, expanded therapeutic opportunities, and increased survival for many patients. Yet they have also revealed new forms of complexity. Clinical decisions are increasingly characterised by uncertainty and probabilistic reasoning. The growing use of artificial intelligence and algorithm-based decision support raises questions of transparency, explainability, accountability, and bias. Precision medicine challenges clinicians to integrate highly individualised biological information with equally individualised patient preferences and life circumstances. At the same time, societies have become more culturally diverse, ethically pluralistic, and increasingly attentive to issues of equity, inclusion, and social justice. Consequently, excellence in oncology can no longer be measured solely by scientific innovation or technical performance. It also depends on the ability to understand and respond to the human complexity that accompanies every experience of cancer.

This recognition represents one of the defining challenges of contemporary oncology. Modern cancer care seeks not only to prolong survival or control disease but also to preserve quality of life, psychological well-being, dignity, and personal meaning throughout the entire cancer journey. Clinical excellence therefore requires more than scientific expertise. It demands an approach capable of integrating biological knowledge with ethical reflection, effective communication, cultural awareness, and a deep understanding of the lived experience of illness.

The "atypical" set of chapters that follow argues that meeting this challenge requires a broader conceptual framework than those traditionally adopted within medical education. We propose Oncohumanities as an interdisciplinary field that brings together insights from medicine, ethics, sociology, psychology, communication sciences, neuroscience, and the health humanities to illuminate the full human experience of cancer. Rather than representing an alternative to scientific oncology, Oncohumanities seeks to complement and strengthen it, recognising that scientific excellence and human understanding are not competing ideals but mutually reinforcing dimensions of professional practice.

The emergence of Oncohumanities reflects a broader historical evolution in medicine itself. Understanding why such a framework has become necessary requires looking beyond recent technological advances to consider the changing ways in which medicine has understood disease, patients, and the goals of clinical care. The movement from disease-centred medicine to *patient-centred care*, and ultimately towards human-centred oncology, provides the intellectual context within which Oncohumanities has developed.

For much of the twentieth century, clinical medicine was shaped by a *disease-centred paradigm*. The remarkable advances of modern biomedical science transformed the understanding of disease by identifying its biological mechanisms and developing increasingly effective diagnostic and therapeutic interventions. Within this framework, the principal task of the physician was to recognise pathological processes, establish an

accurate diagnosis, and prescribe the most appropriate treatment. This approach generated extraordinary scientific progress and remains the indispensable foundation of contemporary medicine.

Its very success, however, also revealed its limitations. By focusing primarily on the biological mechanisms of disease, the disease-centred model often overlooked the subjective experience of illness and the broader psychological, social, cultural, and existential contexts in which disease is lived. Patients could become identified with their diagnosis, while the personal meanings, relationships, values, and life circumstances that shape the experience of illness received comparatively little attention. Although the biomedical model dramatically improved the capacity to treat disease, it proved less well equipped to address the complexity of caring for the person who lives with it.

From the second half of the twentieth century onwards, medicine progressively responded to these limitations through the development of *patient-centred care*. Influenced by advances in bioethics, psychology, sociology, and the social sciences more broadly, increasing importance was given to patient autonomy, informed consent, shared decision-making, and respect for individual preferences. This represented far more than a modification of clinical practice; it marked a profound transformation in the philosophy of healthcare. Rather than asking only, *What disease does this patient have?*, clinicians increasingly began to ask, *What matters to this patient?* The patient's values, goals, and preferences became integral components of clinical decision-making, fundamentally reshaping the relationship between clinicians and those they cared for.

Patient-centred care has become one of the defining achievements of modern medicine and remains an essential foundation of high-quality oncology. It has promoted more respectful relationships, improved communication, strengthened patient engagement, and recognised the ethical importance of autonomy and shared decision-making. Few would question its enduring value or the profound contribution it has made to improving healthcare.

Yet the continuing scientific, technological, and social transformation of oncology now invites a further conceptual evolution. Precision medicine, rapidly expanding technological capabilities, artificial intelligence, and increasingly complex therapeutic pathways have not only multiplied the information available to clinicians but have also made clinical decisions more uncertain, more individualised, and more deeply embedded within the realities of each person's life and individuality. At the same time, demographic change, cultural diversity, and widening awareness of social inequalities have highlighted dimensions of cancer care that extend beyond clinical decision-making alone.

In this context, the concept of the patient, although indispensable within healthcare, no longer fully encompasses the reality of the individual living with cancer. People do not cease to be parents, partners, professionals, citizens, believers, or members of their communities when they become patients. Nor are they defined solely by their capacity to participate in therapeutic decisions. Illness unfolds within a biography rather than a medical record, shaping and being shaped by personal identity, family relationships, cultural traditions, spiritual beliefs, social conditions, hopes, fears, and future aspirations.

For this reason, the defining question of contemporary oncology extends beyond *What matters to this patient?* It becomes, more fundamentally, *Who is this individual?* This question does not replace the principles of *patient-centred care* but enlarges their scope. It recognises that understanding preferences and values requires first understanding the individual from whom those preferences and values emerge.

This shift marks the transition from patient-centred oncology to human-centred oncology, which does not diminish the importance of scientific evidence, clinical expertise, or patient autonomy. Rather, it situates each of these within a broader understanding of the human being. Every therapeutic decision is embedded within a person's identity, relationships, vulnerabilities, aspirations, and social world. Consequently, biological, psychological, ethical, social, cultural, and spiritual dimensions of illness should not be regarded as parallel domains of care but as interconnected aspects of a single clinical reality.

Human-centred oncology therefore represents not a rejection of previous models but their maturation. Disease-centred medicine taught us how to understand cancer; patient-centred medicine taught us how to respect the individual's voice; human-centred oncology challenges us to care for the whole individual whose life is transformed by cancer. It is within this broader vision of medicine that the concept of Oncohumanities finds its

intellectual foundation.

The transition towards human-centred oncology requires a corresponding transformation in the way oncology is conceived, taught, and practised. Scientific knowledge and technical expertise remain the essential foundations of cancer care; however, the increasing complexity of contemporary oncology demonstrates that they are not sufficient on their own. The ability to interpret molecular profiles, select targeted therapies, apply advanced technologies, and evaluate clinical evidence must be accompanied by the ability to communicate effectively, reason ethically, understand uncertainty, appreciate diversity, and recognise the personal meanings that individuals attach to illness.

This broader vision of oncology requires clinicians who are able to integrate different forms of knowledge. Cancer is simultaneously a biological phenomenon, a psychological experience, a social reality, an ethical challenge, and an existential event. These dimensions cannot be separated without losing part of the reality of the individual affected by the disease. A tumour may be defined through molecular alterations, pathological characteristics, and clinical parameters; however, the experience of having cancer cannot be reduced to these dimensions alone. It is lived through emotions, relationships, personal histories, cultural and spiritual identities, and expectations for the future.

Oncohumanities emerges from this recognition. It represents an interdisciplinary framework that integrates the human sciences and humanities into oncology in order to deepen understanding of the individual patient, the clinician-patient relationship, and the ethical and social contexts in which cancer care takes place.

Oncohumanities is founded on a simple but profound premise: oncology is fundamentally a relationship between human beings. Every encounter between an oncologist and a cancer patient involves not only the exchange of clinical information but also an encounter between two individuals, each with their own perspectives, values, emotions, experiences, and vulnerabilities. The quality of this relationship influences how information is understood, how decisions are made, how uncertainty is experienced, and how patients adapt to the challenges of illness.

Within this perspective, oncologists are not merely technical experts who deliver diagnoses and treatments. Their words, attitudes, communication styles, ethical sensitivity, and capacity for reflection shape the meaning that patients attribute to their illness and to the care they receive. The clinician's humanity is therefore not an optional personal quality added to professional competence; it is an integral component of clinical excellence.

This understanding is increasingly supported by scientific evidence. Research in neuroscience and behavioural medicine has demonstrated that interpersonal factors within healthcare relationships can influence processes involved in stress regulation, symptom perception, treatment adherence, psychological adaptation, and overall well-being. Trust, empathy, respectful communication, and emotional attunement are not simply desirable qualities that improve patient satisfaction; they are clinically relevant elements that can affect the way individuals experience illness and engage with treatment. For this reason, humanistic competencies should be considered evidence-based dimensions of oncology practice. Communication, empathy, ethical reasoning, cultural awareness, and the ability to navigate uncertainty are not secondary skills or additional forms of professional enrichment. They are fundamental competencies that contribute to safer decisions, stronger therapeutic relationships, improved patient experiences, and higher-quality care.

Oncohumanities therefore proposes an expanded understanding of oncology professionalism. The excellent oncologist is not only the clinician who possesses the most up-to-date scientific knowledge or technical expertise, but also the clinician who can integrate this knowledge within the complexity of human life. Excellence requires the capacity to move between molecular mechanisms and personal narratives, between statistical probabilities and individual fears, between therapeutic possibilities and personal values.

Oncohumanities provides the conceptual space in which these dimensions can converge since the goal of human-centred oncology is not merely to treat cancer more effectively, but to care more completely for the individuals whose lives are affected by cancer. The future of oncology will depend not only on what clinicians know about disease, but also on how deeply they understand the individuals entrusted to their care. The recognition that human understanding is an essential dimension of oncology practice has important implications for medical education. If human-centred

oncology represents the future direction of cancer care, then oncology training must extend beyond the acquisition of biomedical knowledge and technical skills. Future oncologists must be prepared not only to interpret scientific evidence and apply increasingly sophisticated treatments but also to understand the ethical, psychological, social, and existential dimensions of the illness experience.

This need provides the foundation for the educational programme Learning Oncohumanities to Care, which was developed to systematically integrate the principles of Oncohumanities into oncology education and clinical practice. The programme addresses areas that are often considered complementary to scientific training, ethics, communication, risk and uncertainty, diversity and inclusion, and supportive care, but that are, in reality, essential components of professional competence in contemporary oncology.

The purpose of Learning Oncohumanities to Care is not to transform oncologists into anthropologists, sociologists, ethicists, or communication specialists. Rather, it aims to educate clinicians who are more reflective, intellectually integrated, and professionally accomplished. It seeks to cultivate oncologists who recognise that caring for people with cancer requires the ability to combine scientific expertise with curiosity about human experience, technical competence with ethical awareness, and clinical decision-making with genuine understanding.

Within this perspective, the oncologist is called upon to develop a broader form of expertise. This includes the ability to communicate complex information clearly, discuss prognosis and uncertainty honestly and compassionately, recognise the influence of cultural and social factors on health, identify ethical challenges, and appreciate the different ways in which individuals understand illness and make decisions about their care.

For this reason, the six chapters that follow adopt an intentionally unconventional approach. Rather than presenting exhaustive theoretical discussions, they offer oncologists a concise, accessible, and practically oriented collection of concepts and tools derived from the field of Oncohumanities. Each chapter addresses a fundamental dimension of human-centred oncology and translates theoretical insights into practical guidance that can be incorporated into everyday clinical practice.

The first chapter explores the neuroscientific foundations of the oncologist-patient relationship, examining how interpersonal connection, communication, and trust influence the individual's neuronal activity. The second chapter focuses on the communication of bad news, one of the most challenging and meaningful responsibilities in oncology. The third chapter addresses the communication of risk and uncertainty, providing a framework for navigating probabilistic information in ways that support understanding and shared decision-making. The fourth chapter examines diversity and inclusion, highlighting the importance of recognising differences in culture, identity, social circumstances, and personal values. The fifth chapter discusses supportive care as an essential component of comprehensive oncology, emphasising the need to address suffering and quality of life throughout the cancer trajectory. The sixth and final chapter explores ethics, providing tools for reflection and decision-making when clinical choices involve complex moral dimensions.

Together, these chapters do not seek to provide a complete encyclopaedia of the human dimensions of oncology. Rather, they represent an invitation to adopt a broader vision of what it means to be an oncologist in the twenty-first century. They encourage clinicians to view cancer not only as a biological process to be understood and treated but also as a profound human experience requiring knowledge, sensitivity, and responsibility.

The future of oncology will depend on continued scientific discovery, technological innovation, and therapeutic progress. Yet the ultimate measure of excellence will remain the ability to place these achievements at the service of the person behind the disease. The challenge of contemporary oncology is therefore not only to understand cancer more precisely, but also to understand more deeply the individuals whose lives are transformed by it.

Oncohumanities represents this commitment: the pursuit of an oncology in which scientific rigour and human understanding are not separate aspirations, but inseparable foundations of excellent care.

CHAPTER 1

01

What are the physiological effects of the doctor-patient relationship?

Fabrizio Benedetti

IN THIS CHAPTER

1.1 Is there a physiology of the doctor-patient relationship?
1.2 How can the physiology of the doctor-patient encounter be studied and understood?
1.3 What is a placebo exactly, and how is it related to the doctor-patient encounter?
1.4 How does a placebo work?
1.5 Do placebos and positive doctor-patient interaction always work?
1.6 What is the nocebo effect?
1.7 Is the action of drugs the same if patients do not know they are taking them?

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Fabrizio Benedetti, MD is Professor of Medicine and Neuroscience for the Innovative Clinical Trials & Healthcare Initiative, Zermatt, Switzerland and a former professor of Neurophysiology at the University of Turin. He has been nominated member of The Academy of Europe (MAE), section of Physiology & Neuroscience, London, UK

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He is author of the book Placebo Effects (Oxford University Press, 4th Edition, 2027), which received the Medical Book Award of the British Medical Association in 2009. In 2012 he received the Seymour Solomon Award of the American Headache Society, in 2015 the William S Kroger Award of Behavioral Medicine from the American Society of Clinical Hypnosis. In 2015 he was nominated member of the Council of Scientists of the Human Frontiers Science Program Organization. In 2023, he received the Lifetime Achievement Award by the Society for Interdisciplinary Placebo Studies.

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1.1

Is there a physiology of the doctor-patient relationship?



The doctor's words, behaviours and attitudes change the patient's brain

1.1

Is there a physiology of the doctor-patient relationship?

Although the question may appear weird and unusual, today a true physiology of the doctor-patient encounter is emerging as an interesting neuroscientific approach to understand what is going on in the patients' brain when they interact with health professionals.

The doctor's words and behaviours may have a profound impact on the patient and today we are beginning to understand the changes that take place in the patient's brain when s/he interacts with her/his therapist.

Besides this new neuroscientific knowledge, which helps understand how the human brain works, several clinical implications are emerging in routine medical practice, for example the changes that occur in course of a disease and/or symptom and in the response to a treatment.

It should be pointed out, however, that these effects are not present in all conditions, but only when the psychological component of illness is important. For example, in oncology, there is no scientific evidence that a good doctor-patient relationship can stop cancer growth, however it can change the perception of symptoms such as pain. Therefore, whereas the doctor's positive words do not seem to affect cancer progression, they can affect cancer pain and other symptoms such as nausea.

1.2

How can the physiology of the doctor-patient encounter be studied and understood?



In clinical trials, some patients receive a fake treatment (placebo), thus there is no effect of any treatment (e.g. a drug), however the doctor-patient relationship is maintained.

1.2

How can the physiology of the doctor-patient encounter be studied and understood?

To study and understand the relationship between doctors and their patients, the clinical trial is an excellent opportunity to analyse the patients who receive the fake treatment, namely, the placebo. Therefore, the placebo acquires a crucial role in this new scientific knowledge, because no treatments are administered, however the doctor-patient interaction is maintained.

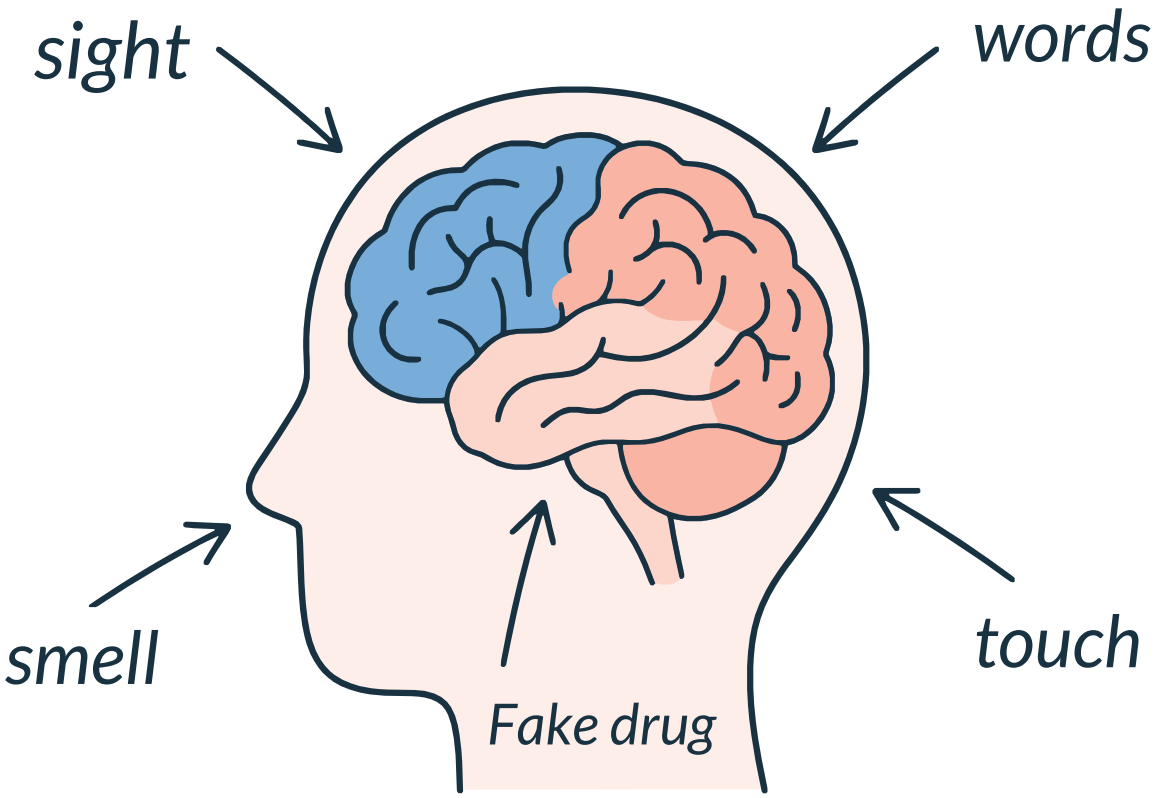
By definition, a placebo is a fake treatment with no specific therapeutic properties. Typical examples are flour or talc pills, syringes with saline solution inside, medical devices turned off.

In clinical trials, active treatments are compared with placebos in order to evaluate the superiority of the former compared to the latter. If there is no difference between the two treatments, it means that the observed improvement is attributable to factors other that the specific effects of the therapy under test.

Indeed, what is really interesting and challenging is the clinical improvement that may take place in those patients who receive a placebo. Several conditions show striking improvements after placebo administration, like pain, motor disorders, psychiatric disorders, and immune responses.

1.3

What is a placebo exactly, and how is it related to the doctor-patient encounter?



A placebo (fake drug) is given within a sensory psychosocial context, which induces positive psychological effects, including physical and emotional well-being.

1.3

What is a placebo exactly, and how is it related to the doctor-patient encounter?

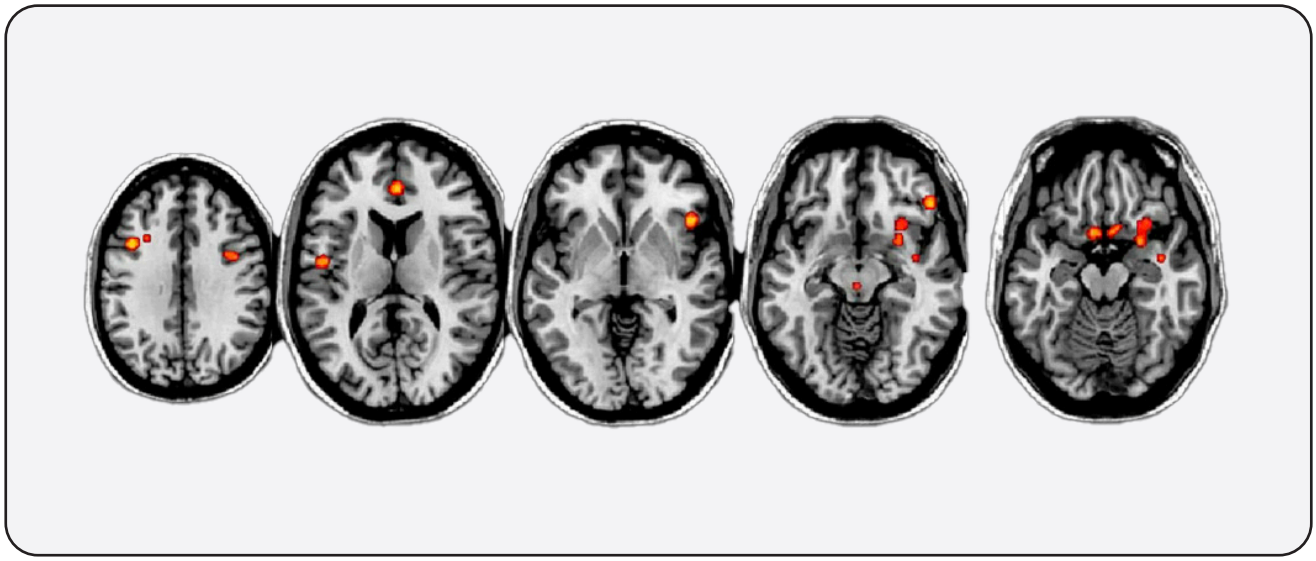
The placebo effect or response is the effect/response following the administration of a placebo. However, it is important to emphasize that placebo response and placebo effect have different meanings. Whereas the former includes factors related to the observed clinical improvement after placebo administration, including psychological factors, spontaneous remissions and experimenter's biases, the latter is related to the patients' psychological reactions following the administration of placebo. These definitions are not different from the definitions of drug response and drug effect: the former is the global response to the drug, including psychological factors and spontaneous remission, whereas the latter is the specific pharmacodynamic effect. The distinction between placebo response and effect leads us to a second distinction. Pragmatic clinical trials aim to study placebo responses, that is, merely whether an active treatment is superior to a placebo, regardless of the factors involved in the improvement, whereas explanatory clinical trials are aimed at investigating placebo effects, namely, at explaining the underlying psychobiological mechanisms.

Therefore, it is the placebo effect that is related to the doctor-patient relationship and not the placebo response. In fact, the placebo effect is due to all those psychological and social factors that are crucial in the interaction between doctors and patients.

The doctor's words, the smell of a drug, the sight of medical environment, to be touched by medical devices, are all verbal and nonverbal sensory stimuli that tell the patient "You will feel better in a while". On the other hand, patients' expectations, beliefs, trust and hope play a key role in the therapeutic encounter.

1.4

How does a placebo work?



The administration of a placebo (i.e., of positive verbal suggestions) activates neural networks in the prefrontal cortex and in the limbic system of both hemispheres.

1.4

How does a placebo work?

The administration of a placebo, which is characterised by positive verbal suggestions and a good interaction with patients, can activate different neural networks. An important neural circuit that is triggered by placebo administration is in the prefrontal cortex and involves the patient's expectations of improvement, trust in doctors and medicine, beliefs and hope. Another circuit that is activated is in the limbic system, which is crucial in emotional regulation, thus inducing positive emotions and physical/emotional well-being.

From a biochemical and pharmacological viewpoint, these networks use opioid systems, endocannabinoids, dopamine, which are the very same biochemical pathways that are used by drugs in routine medical practice.

For example, in pain, morphine binds to the opioid receptors in the central nervous system, but expectations of receiving morphine activates the very same receptors (even though a placebo is given).

Therefore, placebos and drugs share common mechanisms of action. Positive verbal suggestions and a positive relationship with patients can trigger brain mechanisms that are similar to those activated by narcotic drugs.

Not all patients show these psychobiological effects, thus there are placebo responders and non-responders. The future challenge for medicine and neuroscience is to understand why. As far as we know today, at least three hypotheses are under scientific scrutiny:

1) Different genetic variants may be involved.
2) Different personality traits may play a role.
3) Patients can learn to respond to placebo in different moments of life.

1.5

Do placebos and positive doctor-patient interaction always work?

No placebo effects

Psychological factors not important

e.g., infectious diseases and antibiotics, general anaesthesia, contraception, cancer

Large placebo effects

Psychological factors crucial

e.g., neuropsychiatric disorders, pain and fatigue, motor disorders, physical performance

Medical conditions and therapeutic interventions range from those where there are no, or very small, placebo effects to those where placebo effects are large.

1.5

Do placebos and positive doctor-patient interaction always work?

Placebo and good doctor-patient interactions do not work everywhere because psychological factors affect illnesses in different ways: some are sensitive to psychosocial and emotional factors whereas others are not sensitive at all. A placebo antibiotic cannot kill the bacteria of pneumonia and a placebo contraceptive cannot prevent pregnancy. Likewise, there is no scientific evidence of placebo effects for drugs such as anticoagulants and anti-platelet drugs, and for conditions such as osteoporosis or many cardiovascular diseases, and the list of conditions insensitive to placebos would be endless.

Therefore, it is important to stress that cancer pain and cancer fatigue are different from cancer itself. Pain and fatigue can be affected by positive verbal suggestions whereas cancer growth cannot, at least as far as we know today.

1.6

What is the nocebo effect?



A placebo can produce negative effects if the patient believes and expects to experience adverse events and to get sick. This is the nocebo effect, which is due to the negative expectations of clinical worsening. Negative expectations induce anticipatory anxiety and negative emotions, e.g. in the limbic system and in the orbitofrontal cortex, which in turn lead to the nocebo effect.

1.6

What is the nocebo effect?

The nocebo effect goes in the opposite direction compared to the placebo effect. This is due to the patient's negative expectations and beliefs about clinical worsening. Indeed, in many clinical trials, those patients who receive a placebo can experience adverse events when they expect adverse events. It is a typical negative psychological effect, in which anticipatory anxiety plays a crucial role.

For example, the expectation of excruciating pain triggers anticipatory anxiety mechanisms, e.g. in the limbic system and in the orbitofrontal cortex, which in turn activates cholecystokinin (CCK), a substance that facilitates pain transmission.

The limbic system is responsible for emotional regulation, for example negative emotions. The orbitofrontal cortex is one of the regions responsible for anticipatory anxiety. In routine medical practice and in everyday life, many situations and circumstances produce negative psychological effects (nocebo effects). The following situations are the most common:

1) Negative doctor-patient relationship.
2) Badly and poorly communicated negative diagnoses.
3) Anticipation of invasive procedures.
4) Reading the adverse events in the medicine package leaflet.
5) Exaggerated communication and alarmism by the media (which generate mass phenomena).

1.7

Is the action of drugs the same if patients do not know they are taking them?



Many drugs are less effective, or not effective at all, if they are administered covertly (unbeknownst to patients). This represents the best evidence that the doctor-patient interaction and communication is crucial in the therapeutic outcome.

1.7

Is the action of drugs the same if patients do not know they are taking them?

The best evidence that the doctor-patient interaction plays a crucial role in the therapeutic outcome comes from the hidden administration of drugs. This condition is characterised by drug administration through a computer unbeknownst to patients. The crucial point here is that patients do not expect anything because they do not know that a drug is being given.

Many drugs have been tested in this way, particularly painkillers such as morphine, buprenorphine, tramadol, ketorolac and metamizole, as well as anxiolytic drugs like diazepam and nonpharmacological interventions such as deep brain stimulation.

In all these conditions, the hidden administration of the treatment is less effective, or not effective at all, compared to an open administration (in full view of the patient according to routine clinical practice).

Therefore, the patient's expectations about the therapeutic outcome and the trust in the doctor and the therapy play an essential role. If patients' expectations, trust and hope are not nurtured and boosted, many therapies are less effective.

CHAPTER 2

02

How to Communicate Sad and Bad News

Luzia Travado

IN THIS CHAPTER

2.1 Why Communication Matters
2.2 The SPIKES Protocol
2.3 Responding to Emotions
2.4 Communication in Advanced Disease

About the author



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Luzia Travado is **Senior Psycho-oncologist, Clinician and Researcher** in the Breast Department at the Champalimaud Foundation, Lisbon, Portugal. She is also **Invited Associate Professor of Clinical and Health Psychology** at the Piaget Institute, Almada, Portugal; **President Emeritus** of the International Psycho-Oncology Society (IPOS); **Senior Faculty Member and Advisory Board Member** of the European School of Oncology (ESO); and **Co-chair of the Survivorship and Quality of Life Network** at the European Cancer Organisation (ECO). She has over 40 years of experience, and has made major contributions to psychosocial oncology care, cancer communication, and the education of oncology professionals across Europe. She led the European Partnership for Action Against Cancer (EPAAC) survey on psychosocial oncology care resources and has delivered communication skills training nationally and internationally through IPOS, ESMO Preceptorships, and ESO educational programmes.

She has also played a key role in advancing European cancer policy by promoting psychosocial care as an essential component of quality cancer care and advocating for its recognition as a fundamental human right.

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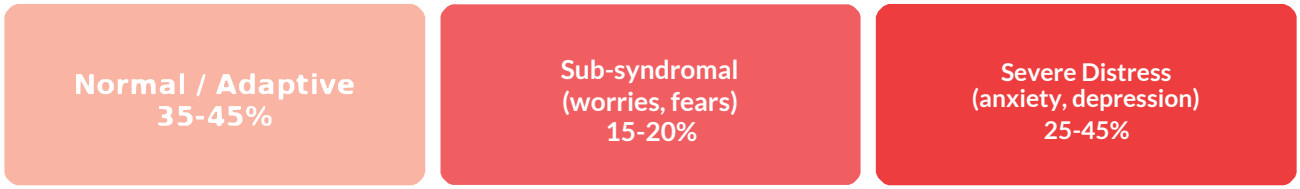
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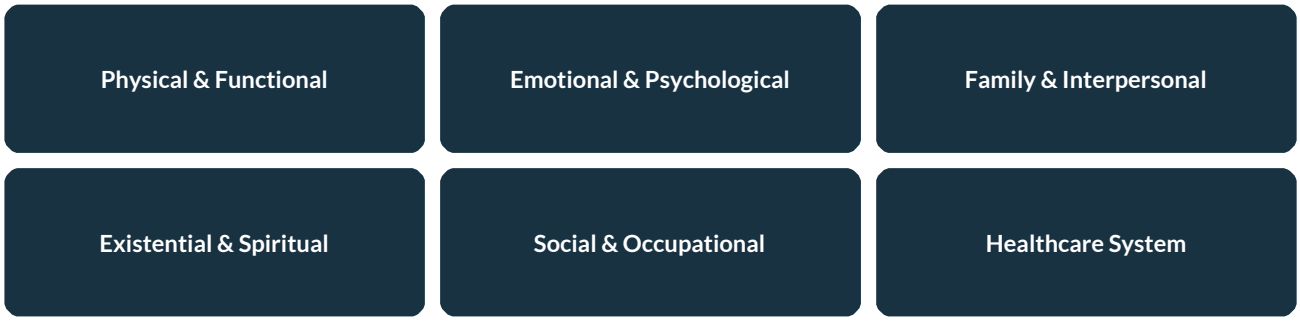
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2.1

Why Communication Matters



Distress continuum — adapted from Holland, IPOS 2005



Six domains of cancer impact — adapted from Koch & Mehnert, IPOS 2005

Keywords: Cancer-related distress · Patient-centered communication · Core clinical competency · Burnout prevention

2.1

Why Communication Matters

Cancer triggers distress across multiple, interacting domains: physical symptoms and functional loss; emotional responses such as fear, sadness and loss of control; disruption of family and social roles; existential and spiritual questioning; social and financial strain; and, frequently, frustration with an impersonal healthcare system (Koch & Mehnert, IPOS 2005). Along this continuum, roughly 35-45% of patients show a normal adaptive response, 15-20% present sub-syndromal worries and fears, and 25-45% experience severe distress meeting criteria for anxiety, depression or adjustment disorder (Holland, IPOS 2005).

Because so much of this suffering surfaces - or is missed - in conversation, communication is not a soft add-on to cancer care: it is a core clinical competency, formally recognized as one of six core competencies for physicians by the ACGME. The evidence linking communication quality to outcomes is substantial: good communication is associated with higher patient satisfaction, greater treatment adherence, better health outcomes, reduced anxiety, improved recall and understanding, and fewer malpractice claims (Kissane et al., 2012). It also protects the clinician: physicians who communicate well report less burnout and greater professional satisfaction.

Yet patients consistently report that only around 60% of physicians truly listen, and fewer than half ask about their goals and concerns (Street et al., 2009). Good communication is, quite simply, the first and most immediate form of emotional support that every oncologist can offer a patient. It can be taught and improved; the challenge is that formal training remains inconsistent across Europe, with only 63% of surveyed countries offering communication skills training during medical education, and rarely as a mandatory component (Travado et al., 2015).

2.2

The SPIKES Protocol



Baile, Buckman et al., The Oncologist 2000

Keywords:
SPIKES protocol · Breaking bad news
Messenger vs. message

2.2

The SPIKES Protocol

SPIKES is the most widely adopted protocol for delivering bad news in oncology (Baile et al., The Oncologist, 2000). Its purpose is to separate the messenger from the message: even when the news is bad, the clinician who delivers it thoughtfully remains part of the patient's support system, rather than becoming associated with the news itself.

The six steps build on one another. Setting up the interview means arranging privacy, adequate time, and involving support persons the patient wants present. Perception asks what the patient already understands ("Tell me what you've been told") - this reveals gaps, denial, or unrealistic expectations that must be addressed before new information is given. Invitation checks how much detail the patient wants, and when - information needs shift over the course of illness, and assuming a fixed preference risks either overwhelming or under-informing.

Knowledge is the delivery itself: forecast that bad news is coming ("I'm afraid I have some difficult news"), give information in small chunks, avoid jargon, and check understanding after each chunk rather than delivering a monologue. Emotions is arguably the step most often rushed: patients need their emotional reaction - shock, sadness, anger, denial - acknowledged before they can absorb further facts; the clinician's own emotional response is also worth naming ("This is difficult for me to tell you too"). Strategy & Summary closes the conversation with a concrete plan and next steps, so the patient leaves with both clarity, a solution to the problem, and a sense that someone remains responsible for what happens next.

Used together, these steps convert an inherently distressing encounter into one the patient experiences as informative and supported, rather than abrupt or abandoning.

2.3

Responding to Emotions



Baile, IPOS 2005

Keywords: Empathic response · Validate · Explore · Emotional acknowledgment

2.3

Responding to Emotions

Responding well to emotion is what turns information-delivery into genuine support. Three linked techniques - exploring, validating and empathizing - combine into what patients experience simply as feeling supported (Baile, IPOS 2005).

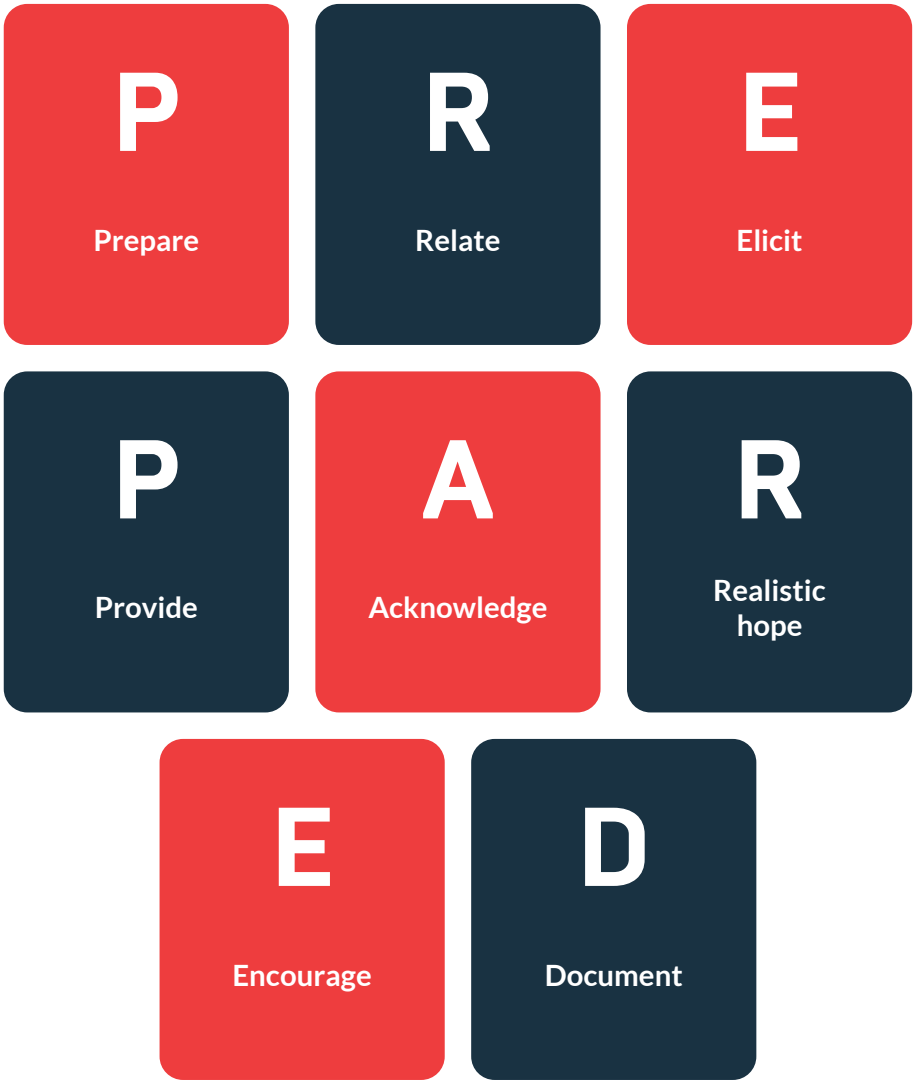
Exploring means inviting the patient to say more when a cue is ambiguous: “Can you tell me what you’re thinking right now?” or “Tell me more about that” - this signals genuine interest rather than assumption. Validating legitimizes the patient’s reaction as normal, not excessive or irrational: “A lot of patients struggle with exactly this decision,” or “That’s something I hear often” - it reduces the isolation of feeling that one’s fear or guilt is abnormal. Empathizing is the explicit acknowledgment of connection: “I can see how upsetting this is,” or “I know this isn’t what you were hoping to hear.”

An empathic response has three internal steps, done largely inside the clinician’s own head first: notice that an emotion is present and name it (sadness, anger, fear); consider its likely source (usually evident from context); then respond in a way that shows the connection has been made. Crucially, empathizing does not require the clinician to feel the same emotion, or to agree with the patient’s interpretation of events - only to acknowledge it as real and understandable. Silence, too, is a form of communication and can itself be a validating response when words would feel intrusive.

Skipping this step is one of the most common errors in bad-news conversations: moving straight from delivering information to discussing next steps, without pausing to let the emotional impact register, leaves patients feeling unheard even when the facts were communicated accurately and kindly.

2.4

Communication in Advanced Disease



Adapted from Clayton et al., Med J Aust 2007

Keywords: Advanced disease communication · Prognosis · End-of-life discussion · PREPARED framework

2.4

Communication in Advanced Disease

As disease advances, communication shifts from delivering a single piece of bad news to an ongoing conversation about prognosis, goals of care and end-of-life planning. The PREPARED framework (Clayton et al., Med J Aust, 2007) extends SPIKES-type principles to this setting.

Prepare means gathering clinical facts beforehand and, where possible, checking what the patient and family already understand and expect. Relate emphasizes building or maintaining rapport before discussing difficult prognostic information - the relationship itself is part of the therapeutic response. Elicit means actively asking what the patient and their caregivers want to know, and how much, rather than assuming a uniform preference for full disclosure. Provide is about tailoring information to the specific needs of both the patient and family, who may want or tolerate different amounts of detail.

Acknowledge requires attending explicitly to emotional responses - fear, grief, anger - exactly as in the Emotions step of SPIKES. Realistic hope means avoiding both false reassurance and blunt pessimism: hope can be reframed toward achievable goals, such as symptom control, quality time, or a peaceful death, rather than cure. Encourage invites further questions and signals that the conversation is not a one-time event. Document ensures that what was discussed and agreed is recorded and communicated to the wider care team, so patients are not asked to repeat painful conversations unnecessarily or given inconsistent information by different clinicians. Together, these steps support patients and families through the most difficult phase of the illness trajectory while protecting continuity and coherence of care.

Luzia Travado, PhD, MSc, ClinPsych

CHAPTER 3

03

How to communicate probabilistic outcomes and risks?

Karin Binder

IN THIS CHAPTER

3.1 Communicating words or numbers?
3.2 Relative or absolute changes in risks and chances?
3.3 Misleading communication using relative changes in risks and chances
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3.7 High sensitivity alone is insufficient
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3.9 Confusing survival rates in early detection
3.10 Communicating statistical information—Take home message

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3.1

Communicating words or numbers?

Physicians often prefer to communicate chances and risks using verbal descriptions.

However, patients frequently **interpret such verbal expressions in very different ways**, which can lead to misunderstandings and unnecessary uncertainty.



Moreover, patients generally prefer statistical information to be communicated in numerical terms rather than through verbal descriptions.



Whenever possible, provide your patients with concrete numerical information regarding **probabilities of recovery**, the **risk of side effects**, or other relevant outcomes.

In the interest of **informed decision-making**, transparent communication of the benefits and risks associated with different treatment options enables patients to make choices that best align with their preferences and values.

3.1

Communicating words or numbers?

To support **informed decision-making**, patients should be provided with comprehensive and balanced information that enables them to make choices that are right for them—that is, to consciously decide whether or not to undergo a specific screening test or initiate a particular treatment. Providing patients with appropriate information facilitates this decision-making process.

But how should statistical information be communicated effectively? **Physicians and other healthcare professionals often avoid presenting specific numerical information, such as probabilities of recovery.** Instead, they tend to rely on verbal descriptions, for example: *"It is very likely that you have disease X,"* or *"We need to conduct some additional tests, but there is no need to worry—only a small proportion of people with these symptoms turn out to have the serious illness Y."* Even when healthcare professionals have access to precise numerical data, many still **prefer such verbal descriptions**.

This practice is problematic for two reasons:

Reason 1: Different patients frequently **interpret the same verbal expressions very differently**. As a result, verbal description may obscure the intended meaning and create unnecessary uncertainty.

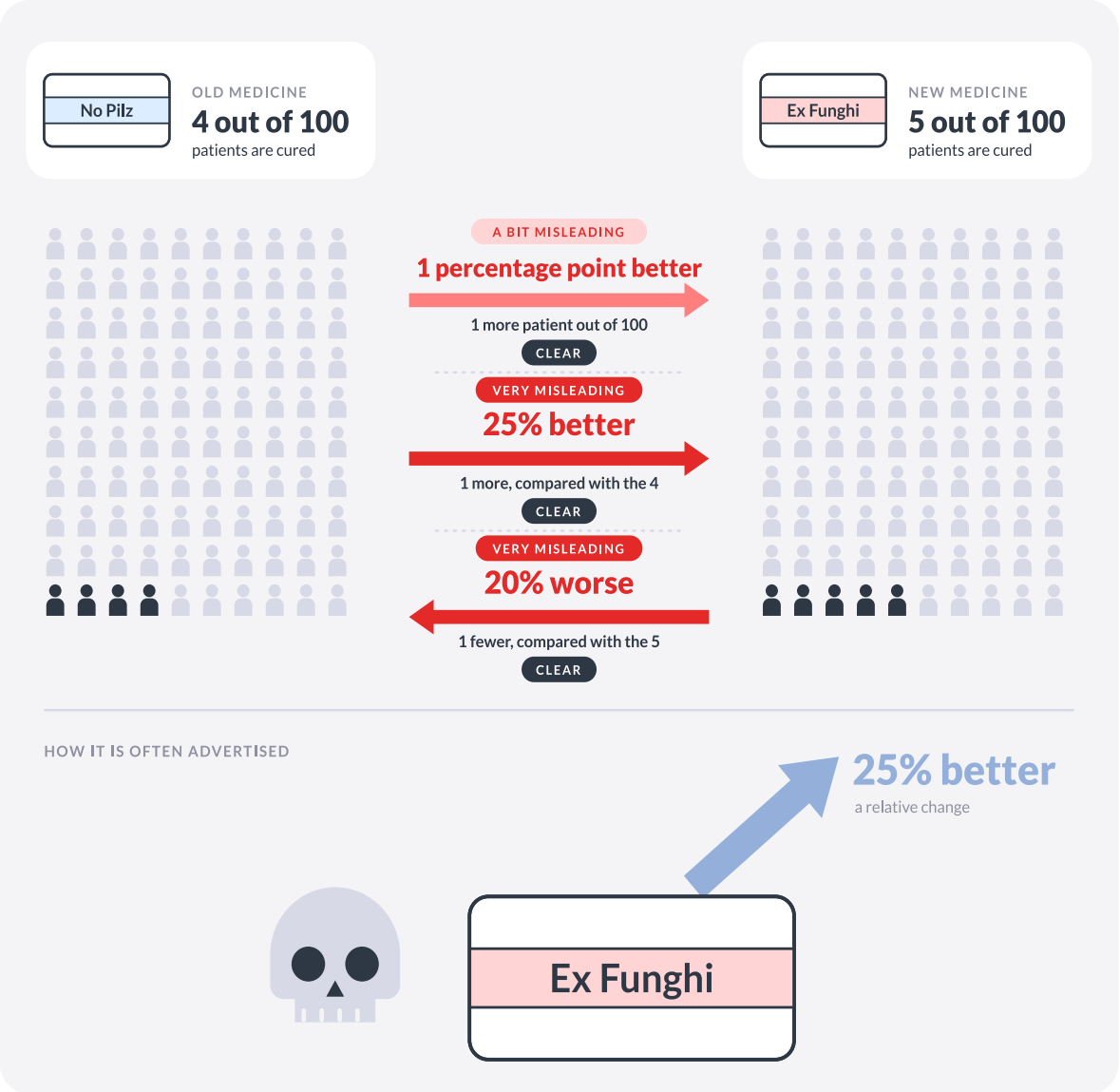
Reason 2: Patients generally prefer statistical information to be communicated in numerical terms rather than through vague verbal descriptions. Numerical information makes them feel better informed and better equipped to make decisions that align with their preferences and values.

Therefore, communicating statistical information in the form of numbers is an important first step. However, even numerical communication is susceptible to misunderstandings and bias. The following examples illustrate **several common pitfalls** and demonstrate how certain numerical representations can be misleading under specific circumstances.

Most problematic, however, is the complete omission of relevant risks or benefits—whether through numbers or verbal descriptions. Informed decision-making requires not only a clear explanation of the **potential benefits of a treatment** but also a transparent presentation of **its associated risks**. When patients have access to this information for different treatment options, they can, together with their physician, choose the course of action that best suits their individual needs and preferences.

3.2

Relative or absolute changes in risks and chances?



Avoid communicating relative changes in risks or chances
Communicate absolute numbers instead

3.2

Relative or absolute changes in risks and chances?

Patients are frequently confronted with numerical information describing **changes in probabilities**. These changes may represent, for example, an increase in the chance of recovery with a new medication or a reduction in the risk associated with a particular treatment.

Consider the information presented in the diagram. Among 100 patients treated with the older medication, *No Pilz*, 4 are cured of the disease. Among 100 patients treated with the new medication, *Ex Funghi*, 5 are cured. Presenting outcomes in **this way is an effective method for communicating changes in the probability of recovery**. Whenever possible, compare **equally sized groups of patients** and report how many individuals in each group experience the outcome of interest. Visual aids, such as the diagram shown here, can further improve understanding and help patients compare treatment options more easily.

However, in the media and in pharmaceutical advertising, changes in probabilities (or proportions) are often communicated in a misleading way by using **relative changes instead of absolute numbers**. In our example, this would mean saying that the new medication, *Ex Funghi*, **increases the chance of recovery by 25%**. This percentage is calculated by relating the one additional patient who is cured to the four patients who are cured with the old medication, *No Pilz*. One out of four corresponds to a 25% increase. This sounds very impressive. However, many people interpret a 25% increase in the chance of recovery to mean that, out of 100 patients, 25 more will be cured with the new medication. As you have seen, this is not what happens in our example. **Relative increases often appear impressive but can be highly misleading and should therefore be avoided.**

From a mathematical point of view, it would even be correct to say that **20% fewer patients are cured with the old medication**, because 4 is 20% less than 5.

Another way to communicate a change in probability is **by using the absolute change**. In our example, 1%—or 1 percentage point—more patients are cured with the new medication, Ex Funghi, than with No Pilz. Here, all 100 patients receiving the medication serve as the reference group. One out of 100 corresponds to a **1% increase**, which sounds less impressive than a relative change but is much closer to what people typically understand when they hear "a 1% increase."

However, presenting **two groups of patients and communicating the absolute numbers of patients who are cured in each group** is the best way to communicate the increase in the chance of recovery.

3.3

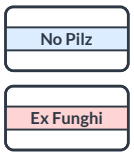
Misleading communication using relative changes in risks and chances

Never mix the reporting of absolute and relative changes expressed as percentages.

HIGHLY IMPRESSIVE MANIPULATION

Mixing relative and absolute changes

Increased chance of recovery



4 out of 100

5 out of 100

RELATIVE CHANGE

The chance of recovery is increased by
25%

Increased risk of side effects



4 out of 100

5 out of 100

ABSOLUTE CHANGE

The risk of side effects is increased by
only 1%

Avoid communicating a relative increase in the chance of recovery and an absolute increase in the risk of a side effects within the same sentence.

Whenever changes of probabilities or proportions are communicated, always ask yourself: Percent of what? What is the corresponding reference group?

3.3

Misleading communication using relative changes in risks and chances

We have learned that changes in probabilities (or proportions) can be communicated as absolute or relative changes, and that communicating relative changes should be avoided. Furthermore, **mixing these different forms of communication is also not advisable** and should be avoided.

Let's take another look at our example with the two medications, *No Pilz* and *Ex Funghi*. We have already seen that **4 out of 100 patients are cured with No Pilz**, whereas **5 out of 100 patients are cured with Ex Funghi**.

To keep the example as simple as possible, now imagine that with *No Pilz*, **4 out of 100 patients experience a side effect**, whereas with *Ex Funghi*, **5 out of 100 patients experience a side effect**. How could we promote our new medication, *Ex Funghi*, in a very impressive way, even though we also have to communicate that it increases the risk of side effects?

It would be **highly misleading (or even manipulative)** to express the increase in the chance of recovery as a **relative change** and the increase in side effects as an **absolute change**, for example:

"Buy our new medication, Ex Funghi. It is great! Compared with the old medication, No Pilz, the chance of recovery increases by 25%. However, to be transparent, there is also an increase in side effects. But don't worry—the risk of side effects increases by only 1% compared with the old medication."

Unfortunately, **this type of communication does occur in practice**, making a newly developed, expensive medication appear more effective than it actually is.

So please keep this in mind: Whenever a change in a probability or proportion is reported—such as an increase in the chance of recovery or a reduction in the risk of a side effect—and that change is expressed as a percentage, always ask, **"Percentage of what?"** What is the corresponding reference group? Is it **all patients receiving the medication**, or only **the patients who were cured with the old medication, No Pilz**? In the latter case, the reported change is a **relative change**, which sounds impressive but does not reflect what most people assume the percentage means.

Therefore, once again: **Avoid communicating relative changes**! Even more importantly, avoid mixing **absolute** and **relative** changes within the same communication.

The **best way to communicate benefits and risks** is to use **absolute numbers**. For example: Out of 100 patients treated with *No Pilz*, 4 are cured, whereas 5 out of 100 patients treated with *Ex Funghi* are cured. At the same time, 4 out of 100 patients treated with *No Pilz* experience a side effect, compared with 5 out of 100 patients treated with *Ex Funghi*.

3.4

Confusing conditional probabilities

In diagnostic situations, frequently information like the **sensitivity** and **false alarm-rate** are communicated. Please consider the following situation:

Probability version	Natural frequency version
The probability of breast cancer is 2 % for a woman who participates in routine screening. (prevalence) If a woman who participates in routine screening has breast cancer, the probability is 80 % that she will have a positive mammogram. (sensitivity) If a woman who participates in routine screening does not have breast cancer, the probability is 10 % that she will have a positive mammogram. (false alarm-rate)	200 out of 10,000 women who participate in routine screening have breast cancer. 160 out of 200 women who participate in routine screening and have breast cancer, will have a positive mammogram. 980 out of 9,800 women who participate in routine screening and have no breast cancer, will also have a positive mammogram.
Question: What is the probability that a woman who participates in routine screening and receives a positive mammogram has breast cancer?	**Question:** How many of the women who participate in routine screening and receive a positive mammogram have breast cancer?
Answer: 14%	**Answer:** 160 out of 1,140

The information on the right side with so called “natural frequencies” (“160 out of 200”) **is much easier for patients to understand** compared to the left side with probabilities.

$$P(B/T^{+}) = \frac{P(T^{+}/B) \cdot P(B)}{P(T^{+}/B) \cdot P(B) + P(T^{+}/nonB) \cdot P(nonB)}$$

$$P(B/T^{+}) = \frac{0.8 \cdot 0.02}{0.8 \cdot 0.02 + 0.1 \cdot 0.98} = 0.14$$

3.4

Confusing conditional probabilities

Diagnostic situations can be communicated in a very confusing or in a very clear and transparent way. For patients, it is often difficult to understand conditional probabilities such as **sensitivity P(T+/B) (**i.e. the probability of having a positive test, T+, given that the individual has the disease, B), **false-alarm rates P(T+/nonB)** (i.e. the probability of obtaining a positive test result, T+, given that the individual does not have the disease, *non*B), and **specificity P(T-/nonB) (**i.e. the probability of obtaining a negative test result, T-, given that the individual does not have the disease, *non*B) of a medical diagnostic test. Let's look at an example of potentially confusing information. Imagine a breast cancer screening situation using mammography. Assume a **prevalence P(B) of 2%**, meaning that about 2% of women in a given age group have breast cancer. Furthermore, assume a **sensitivity P(T+/B) of 80%**, meaning that 80% of women with breast cancer receive a positive test result. Finally, assume a **false-alarm rate P(T+/nonB) of 10%,** meaning that 10% of women without breast cancer also receive a positive test result in mammography screening, even though they are healthy.

Now we want to determine how large the **positive predictive value P(B/T+)** is, i.e. the probability that a woman actually has breast cancer (B), given that she receives a positive mammogram result (**T+**). This probability can, for example, be calculated using **Bayes' theorem** and is (as you can see in the left page) 0.14, that is, 14%.

Most people—including many physicians—struggle to answer this question correctly. However, people understand the information much better when it is translated into so-called **natural frequencies**. Imagine a concrete sample of, for example, 10,000 women. Instead of referring to 2%, we can say that, on average, 200 out of 10,000 women have breast cancer. Instead of stating 80%, we can say that, out of these 200 women with breast cancer, on average 160 will receive a positive test result in mammography screening. And instead of 10%, we can say that, out of the 9,800 women without breast cancer, 980 will nevertheless receive a positive test result, even though they are healthy.

Additionally, we can **translate the question into natural frequencies**: How many of the positively tested women actually have breast cancer? Now it becomes easier to see: There are 160 women with a positive test who truly have breast cancer. However, there are also 980 women with a positive test who do not have breast cancer. In total, there are 1,140 women with a positive test, but **only 160 out of these 1,140 women actually have breast cancer** (which corresponds to 14%).

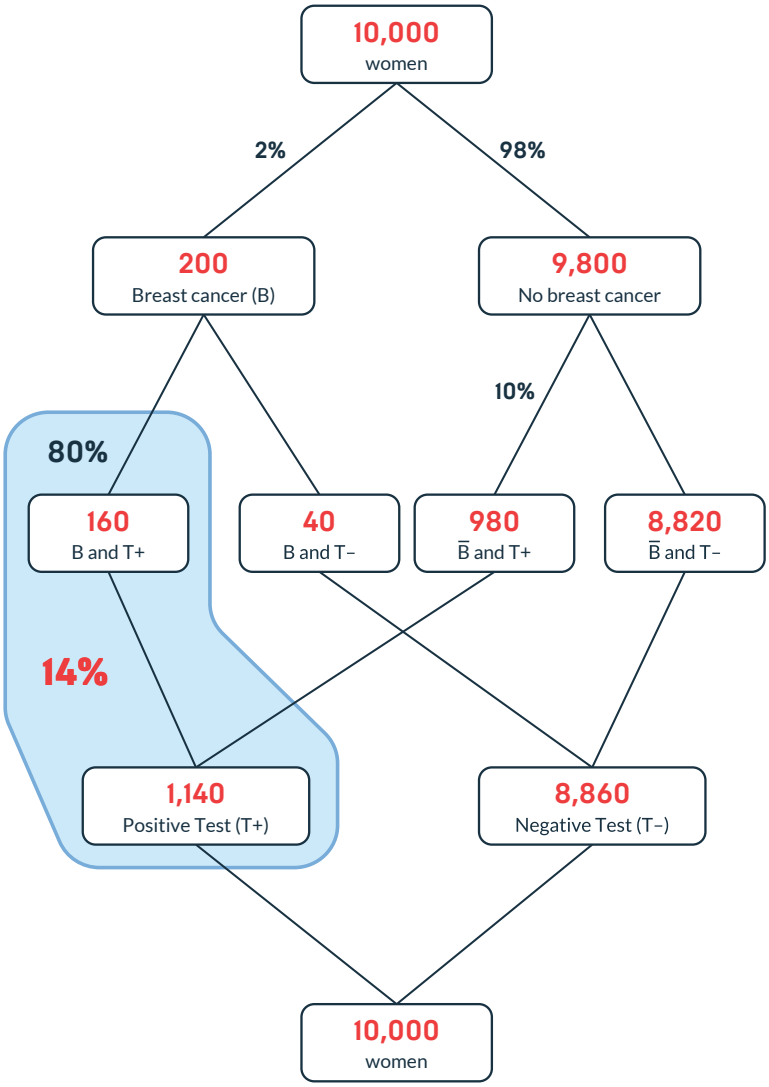
Patients—and also physicians—understand this type of information much better than abstract probabilities.

3.5

Visualize conditional probabilities

Conditional probabilities are often confusing, and most people do not understand them intuitively. It is therefore preferable to communicate so called **natural frequencies** instead (e.g., 160 out of 200 women with breast cancer receive a positive test result).

An even more effective way to communicate statistical information is through **visualizations**.



However, avoid visualizations that only represent conditional probabilities. Please prefer visualizations that also provide natural frequencies, such as the **double-tree diagram** above. **Empirical studies** show that many more people are able to understand the positive predictive value with the help of this type of visualization.

3.5

Visualize conditional probabilities

A further strategy for improving the understanding of confusing conditional probabilities is to **visualize** them, for example using a **double-tree diagram based on natural frequencies**. There is strong empirical evidence that patients understand statistical information better when it is presented in a visual format.

However, diagrams that directly represent conditional probabilities (rather than natural frequencies) are often not very helpful. It is therefore important to use **natural frequencies as the basis of any diagrammatic representation**.

Now it becomes easier to see—compared to the purely textual version of the task—how the **positive predictive value** can be calculated, i.e. the probability of having breast cancer given a positive mammogram result.

Out of 200 women with breast cancer, 160 receive a positive test result. However, out of 9,800 women without breast cancer, 980 nevertheless receive a positive test result, even though they are healthy. In a **double-tree diagram**, it is possible to directly sum all women with positive and negative test results. **In total, 1,140 women receive a positive test result.** Therefore, the positive predictive value is 160 out of 1,140, or 14%.

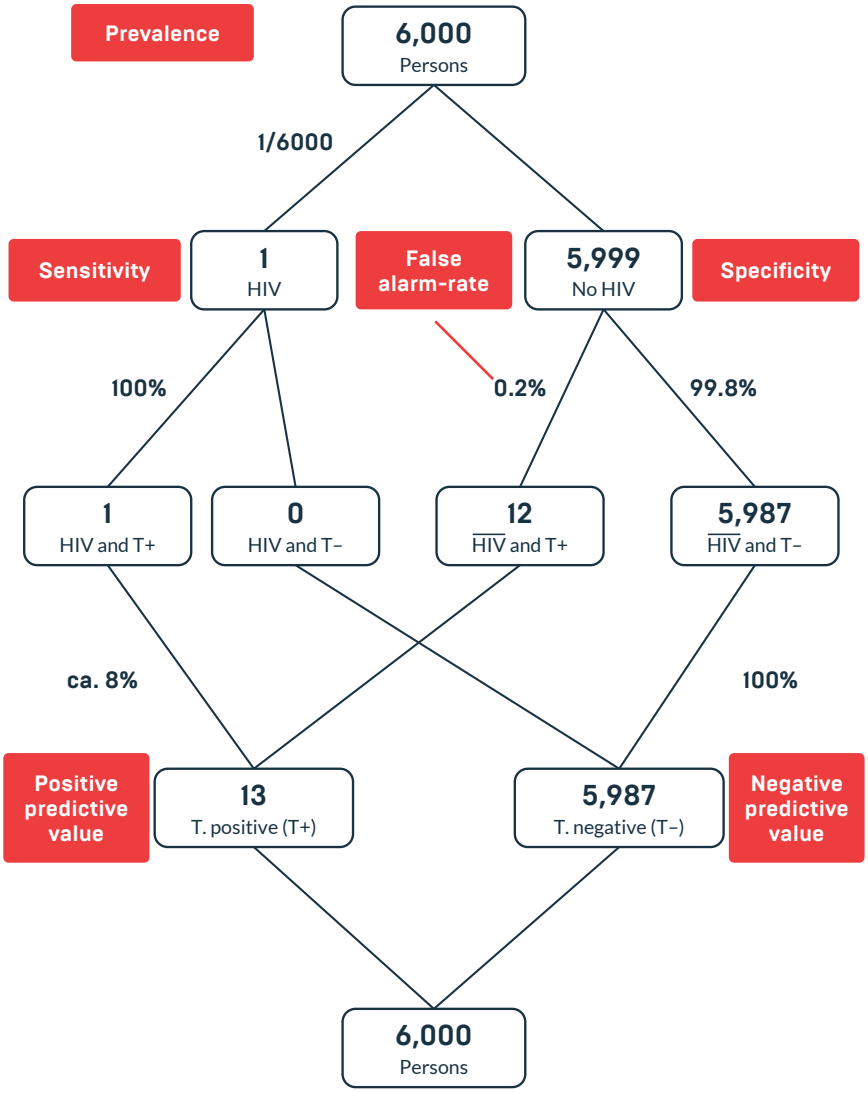
A major advantage of the **double-tree diagram** is that it **simultaneously presents both sensitivity and the positive predictive value**, two measures that are frequently confused. Sensitivity refers to the proportion of positive test results among individuals who are actually ill, whereas the positive predictive value refers to the proportion of truly ill individuals among all those who test positive. In the double-tree diagram, the distinction between these two proportions becomes much clearer.

Presenting double trees based on natural frequencies helps people understand medical diagnostic situations more effectively.

3.6

Do not neglect the base rate!

Despite **favorable test characteristics** (high sensitivity and a low false-alarm rate**), the positive predictive value can sometimes still be very low**. This effect, along with the associated misconceptions, is referred to as **base-rate neglect**.



One medical example is screening for HIV. The test parameters of most HIV tests are excellent. However, the positive predictive value can still be very low due to the low base rate of the disease.

Caution: Whenever the base rate is very low, you may be susceptible to base-rate neglect. The positive predictive value may be much lower than you would expect.

3.6

Do not neglect the base rate!

In medicine, we frequently encounter the following situation:

- **Very good test characteristics**, as in the HIV example: sensitivity is extremely high (close to 100%, or even 100%), meaning that most HIV tests correctly identify all infected individuals. In other words, there are virtually no false-negative results when the test is performed correctly.
- **Very low base rate**: Assume, for example, that only 1 out of 6,000 individuals is infected with HIV. This is a very low prevalence. The proportion of infected individuals in the population is therefore extremely small. Situations with such low base rates frequently occur in screening contexts.

When large segments of the population are tested for a very rare disease, we are dealing with a **low base rate.** Such situations often lead to confusion, as the **positive predictive value can be surprisingly low despite excellent test characteristics**.

Let's take a look at the HIV testing example: The sensitivity of this test is assumed to be **perfect at 100 percent**. Some pharmaceutical companies do, in fact, claim such a high level of sensitivity. This means that the test correctly identifies all infected individuals, provided it is performed correctly.

The false-alarm rate is very low at 0.2 percent. Only 0.2 percent of non-infected individuals incorrectly receive a positive test result.

However, the double tree illustrates why the positive predictive value is remarkably low at around 8%. Because **the population of healthy individuals is so large**—5,999 people—even a minimal false-positive rate results in a high absolute number of healthy people receiving an incorrect positive test result. Specifically, 0.2% of 5,999 individuals equals 12 false positives. In contrast, only a single person with a positive test is actually infected**. Consequently, the vast majority of those who test positive are healthy.** This surprising outcome is driven by the **low base rate**. Ultimately, the double tree with absolute frequencies helps clarify this counterintuitive positive predictive value.

As a heuristic, we suggest a simple rule: if the base rate is extremely low, proceed with caution! Even when a test has excellent metrics, the positive predictive value can still be surprisingly low, as this example demonstrates.

3.7

High sensitivity alone is insufficient



The media frequently highlights the high sensitivity of new detection methods; **however, high sensitivity alone is insufficient.**

My new test: 100% sensitivity



False alarm rate:
Proportion of positive tested persons among healthy persons.
Here: false alarm rate: 100%

To truly assess a test's quality, one must also account for a **low false-positive rate**.

Yet, even with **exceptional test parameters**, the positive predictive value can remain surprisingly low **if the base rate is low**.

3.7

High sensitivity alone is insufficient

Particularly in media reports and pharmaceutical promotional materials, **high sensitivity is frequently placed squarely at the center of attention**. The following extreme example illustrates why this exclusive focus on sensitivity is highly concerning: Imagine I develop a **new diagnostic tool for prostate cancer**. My sole, uncompromising goal is to maximize the test's sensitivity, secondary to all else: I want to detect *every single* individual with the disease, if only because it makes for excellent advertising. To achieve this, I devise the following metric: if a man has a nose, he tests positive for prostate cancer. Since every man has a nose, my test will successfully detect every case of prostate cancer. **Consequently, we have a test with a sensitivity of 100%.**

The flaw in this test, however, is that all other men—including those who are completely healthy—will also receive a positive result simply because they have a nose. Consequently, **the false-positive rate is a staggering 100%**, which is, of course, unacceptable. Yet, considering that many media reports focus exclusively on sensitivity and that most readers fail to question the rate of false alarms, this dynamic creates a prime opportunity for deception. **Therefore, communicating sensitivity as the sole metric must be avoided.** A high-quality medical test requires **not only high sensitivity** but also a **low false-positive rate**.

However, as the previous HIV example demonstrated, **even a combination of high sensitivity and an exceptionally low false-positive rate can still yield a surprisingly low positive predictive value**. This occurs precisely when the **base rate is very low**—meaning that a test, which is actually quite good, is used in a population where only a few people have the disease (as is typically the case with screening methods).

Only when we have data on **both the sensitivity and the false-positive rate** (or, alternatively, the specificity—which is 1 minus the false-positive rate) **and the base rate** is also known, can we determine how effective the test is and calculate the positive predictive value.

3.8

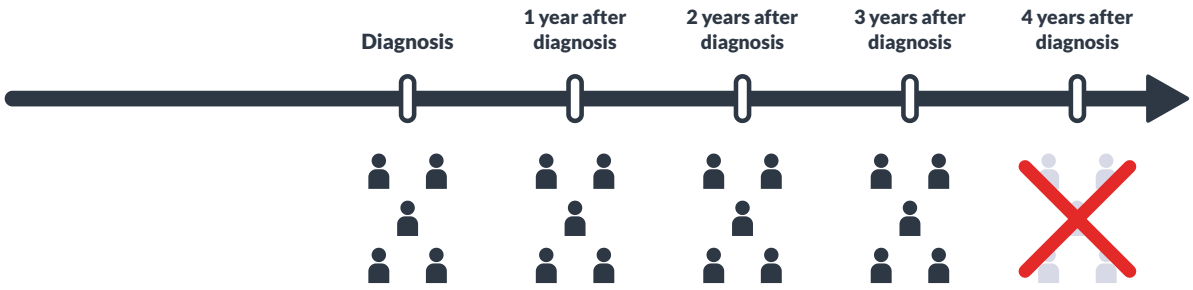
Confusing survival rates

The effectiveness of a treatment or routine screening is often demonstrated using **5- or 10-year survival rates**.

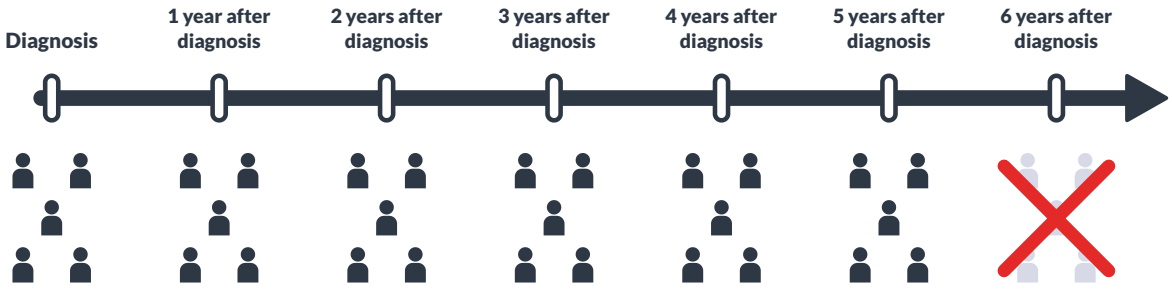
However, these rates can be easily manipulated. **Simply implementing a screening program—and thereby detecting a disease earlier—increases the 5-year survival rate, even if the affected individuals do not live a single day longer.**

A simple thought experiment: Every year, a certain percentage of people are diagnosed with "disease X."

Four years after diagnosis, all these people die from the disease.



5-year survival rate: 0 percent



5-year survival rate: 100 percent, even though nothing has really improved for patients (they simply live longer knowing they have a serious illness).

3.8

Confusing survival rates

5- and 10-year survival rates give the impression of an objective, matter-of-fact presentation of statistics, showing the extent to which a treatment or early-detection measure improves the chances of survival. However, even these parameters can be misleading, as our example demonstrates.

Imagine that a certain number of people fall ill each year, and all of them die exactly four years after their diagnosis. Therefore, in this scenario, the **5-year survival rate is 0%**.

But what happens if a new method allows us to **detect the disease two years earlier**? The bad news is that there is still no medicine to cure these patients. Consequently, they do not live a single day longer—they simply live two years longer knowing they have a serious illness. Although the situation has not improved for these individuals at all (some may prefer knowing earlier, while others may find it a burden), **the 5-year survival rate has now suddenly risen to 100%**.

This example shows that an increase in the survival rate can easily be achieved artificially **by introducing a useless early-detection program**—even for an untreatable disease. To patients**, it may appear as though the implementation of early detection is highly beneficial**. However, the example illustrates that the situation for patients has not improved at all.

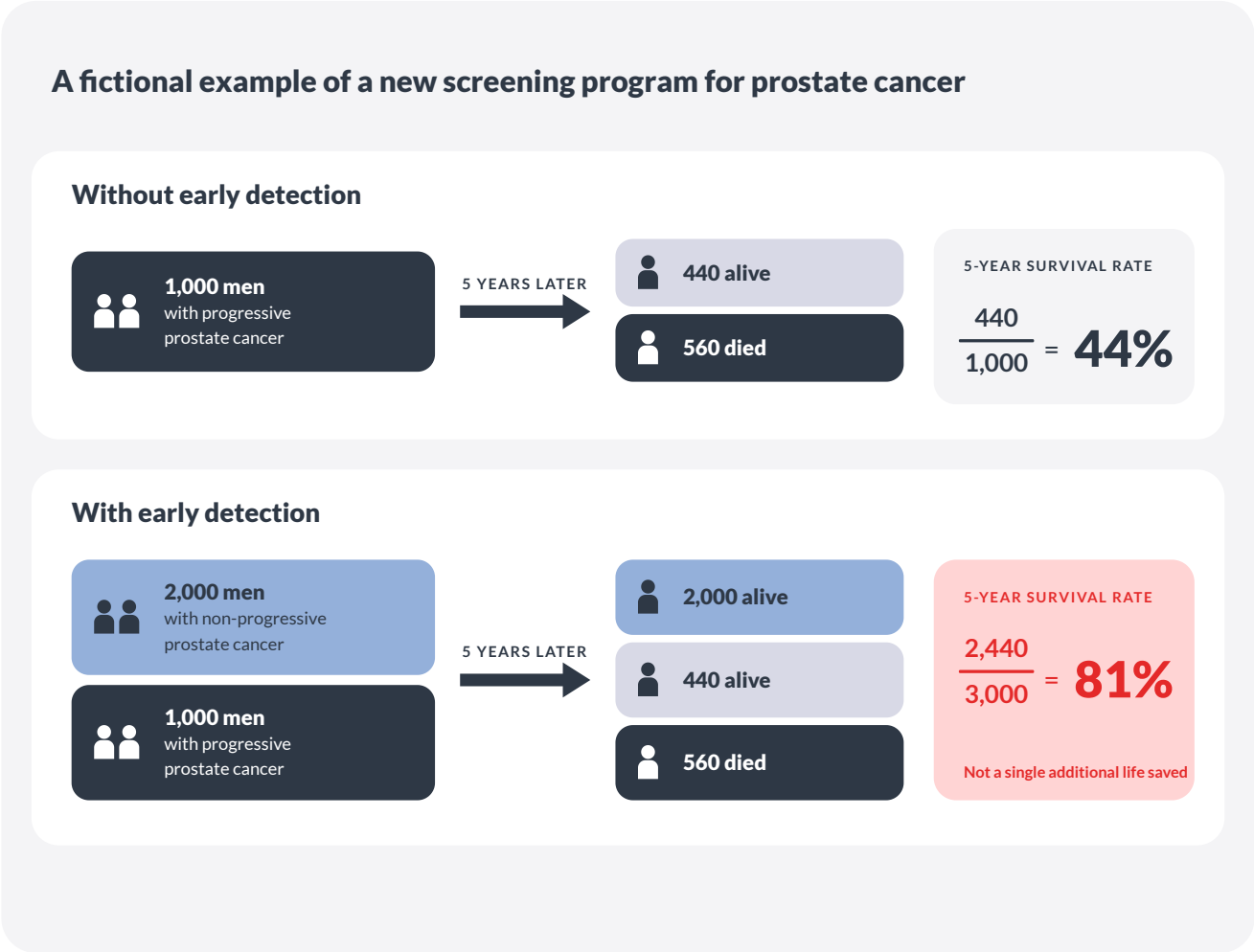
This scenario also demonstrates that implementing a screening method is only worthwhile if, following early detection, **appropriate treatments are available** to cure the disease or at least slow its progression.

This statistical distortion is known as **lead-time bias**. It occurs because early detection merely shifts the date of diagnosis backward, extending the time a person lives *with* the diagnosis without actually delaying the time of death. As a result, the survival statistics look flawless on paper, while the actual life expectancy remains completely unchanged.

Instead of survival rates, the **"number needed to treat"** could be communicated—that is, how many people must be treated to save one life. This information is far more helpful for patients.

3.9

Confusing survival rates in early detection



What if early detection identifies conditions that would never have caused a harm?
Avoid communicating 5- or 10-year survival rates when a new early-detection method has been implemented. Instead, please provide the 'number needed to treat'.

3.9

Confusing survival rates in early detection

Especially when implementing a new early-detection method, 5- or 10-year survival rates can be highly misleading. Let's look at a **fictional example of a new screening program for prostate cancer**. Imagine that without this new early-detection method, 440 out of 1,000 men with progressive prostate cancer are still alive after 5 years, while 560 men have died from the disease. Therefore, the baseline **5-year survival rate in this example is 44%**.

Ideally, early-detection methods are implemented with the goal of **discovering dangerous but treatable stages of a disease**. In reality, however, screening often also leads to the discovery of **non-progressive cancers** that would never have caused any harm.

Imagine, for example, that a completely useless early-detection program is introduced, which **only detects 2,000 men with a harmless, non-progressive type of prostate cancer**. Consequently, after five years, all 2,000 of these men are still alive (now knowing they have prostate cancer). As before, 560 men still die from the progressive form of the disease. However, the five-year survival rate has now drastically shifted. Out of the 3,000 men diagnosed after implementing the new screening method, 2,440 are alive after five years. **Therefore, the five-year survival rate has surged from 44% to 81%, even though not a single additional life was saved.**

What can we learn from this situation? The introduction of new screening methods often leads to the detection of conditions that would never have caused any harm. These individuals then skew the statistics. In our extreme example, it appeared as though early detection was saving many more lives; **in reality, however, this was merely a statistical artifact.** Therefore, when you hear that a screening method has significantly improved 5- or 10-year survival rates, keep this example in mind. **Ask critical questions**—such as how many people are being diagnosed with non-progressive conditions—**before overestimating the potential benefits** of the early detection.

Afar better way to communicate the impact of a new early-detection method is by using the **'number needed to treat' (NNT)**. The number needed to treat is defined as the **average number of patients who must receive treatment to save one additional life**.

3.10

Communicating statistical information Take home message

Communicate numerical data

- Avoid verbal descriptions of probabilities. Communicate numerical data whenever possible
- Patients feed better informed when given exact numbers instead of verbal descriptions

Avoid communicating relative changes in benefits and risks

- Communicate absolute changes instead
- Even better: Use concrete sample groups. Imagine a specific number of people taking Medicine A versus Medicine B, and clearly communicate how many individuals are cured and how many suffer from side effects in both groups.

Communicate the positive or negative predictive value

- Instead of focusing solely on the test's sensitivity, provide information about the positive or negative predictive value whenever possible.
- Patients (and even physicians) frequently confuse sensitivity with the positive predictive value.
- Communicate absolute frequencies instead of confusing probabilities, and use visual aids whenever you have the opportunity.

Don't ignore the base rate

- Even if a medical test has high sensitivity and high specificity, the positive predictive value can still be low if the base rate is low.
- Particularly when screening a large population to detect a rare disease, the positive predictive value is often surprisingly low, despite excellent test parameters.

Avoid communicating survival rates

- 5- and 10-year survival rates can be highly misleading when evaluating early-detection methods.
- Communicate the "numbers needed to treat" instead to provide a clearer picture

3.10

Communicating statistical information Take home message

Patients typically prefer exact numbers over verbal descriptions of benefits and risks, and **they feel better informed when numerical data is shared**.

Please never communicate relative changes in probabilities and risks. For example, avoid statements like: 'The chance of being cured increases by 25%' when, in reality, 4 out of 100 people are cured with the old medication and 5 out of 100 with the new one. While that sounds wonderful, it routinely misleads patients. Instead, communicate absolute changes, such as: 'The chance of being cured increases by 1 percentage point.' **Even better, directly communicate the absolute frequencies: state exactly how many people are cured with the old medicine compared to the new one.**

Be careful when communicating conditional probabilities, such as sensitivity or the false-positive rate. Patients are generally **not interested in sensitivity**—that is, the probability of testing positive given that they have the disease. Instead, they want to know the **positive predictive value**, which is frequently confused with sensitivity. In other words, patients want to know how likely it is that they actually have the disease if their test is positive. Conversely, they want to know how likely it is that they are truly healthy if the test is negative (the **negative predictive value**). It is always best to share these direct, practical probabilities with them.

Beware of ignoring the base rate. Imagine you receive information about a new medical test that is described as excellent because **it features high sensitivity and a low false-positive rate**. However, if this test is used as part of a screening program—where the proportion of truly sick individuals in the population is very small—surprising results can occur: due to this low prevalence, it may still be the case that **only a small fraction of those who test positive are actually sick**.

Avoid communicating **5- or 10-year survival rates**. When new early-detection methods are introduced, these rates almost always rise. Crucially, however, this does not necessarily mean that a single additional life is saved. Communicate the **'number needed to treat'** instead.

CHAPTER 4

04

Centering Diversity in Oncology Care

Maisha Reza, Olubukola Ayodele, Anja Visser, Alison May Berner

IN THIS CHAPTER

4.1 Cultural Diversity: what it is
4.2 Transcultural care
4.3 Ethnic Disparities in Cancer Outcomes
4.4 Barriers to Equitable Cancer Care
4.5 Defining spirituality and spiritual diversity
4.6 Centering spirituality in care
4.7 Gender Diversity: Sex and gender influence cancer risk and management
4.8 Care for Trans and Gender Diverse People with Cancer
4.9 Intersectionality and The Whole-Person Care

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Dr. Alison May Berner (she/her/ella) is a Clinical Senior Lecturer at Queen Mary University of London, and an Honorary Consultant in Medical Oncology. Her mixed-methods programme of research centres on reducing cancer care inequalities according to sex, gender and sexual orientation and she leads the UK Cancer and Transition Service (UCATS).

SUGGESTED READINGS

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4.1

Cultural Diversity: what it is



Case Study 1: Amina's Distrust in Healthcare

Refusal or delay of treatment - linked to traditional healing, stigma, or distrust in healthcare systems. Amina is a 45-year-old Somali woman, recently diagnosed with triple-negative breast cancer. She has lived in the UK for ten years and speaks conversational English, though she often relies on her eldest daughter to interpret during appointments.

Amina is deeply connected to her Muslim faith and community. She expresses discomfort with male clinicians performing physical examinations, citing modesty and cultural expectations. She prefers traditional herbal infusions alongside medical treatments, as they have been effective and passed down as generational medicinal knowledge. During her oncology consultation, the attending physician, Dr. Smith, notices that Amina is hesitant about starting chemotherapy. She says, *"My cousin in Halima died after the chemotherapy made her body too weak. I do not want the same.*

The consultation is running behind schedule, and Dr. Smith, pressed for time, focuses on explaining the urgency of chemotherapy as her best option. He uses some medical terms which Amina nods at and concludes, "This treatment is your best chance for survival. We should start next week."

Amina smiles politely but does not ask questions. **She later misses her follow-up appointment.**

	Key Themes
1	Language barriers and use of family members as interpreters.
2	Cultural perceptions of illness, beliefs about strength, purity, and modern medicine.
3	Gender and modesty preferences influencing comfort with care.
4	Potential power imbalance between clinician and patient.
5	Lack of shared decision-making and reflective listening.
6	Absence of formal integration of cultural safety practices.

4.1

Cultural Diversity: what it is

Culture plays a critical role in shaping how patients understand cancer, engage with healthcare systems, and make treatment decisions. In oncology, where care often involves complex and emotionally charged decisions, recognising cultural influences is essential to delivering safe, person-centred care. Patients' beliefs about cancer causation, stigma, family roles, and acceptable treatments can significantly influence screening uptake, treatment adherence, and end-of-life decision-making.

Cultural competence is one of the most widely used frameworks, referring to the ability of clinicians to interact effectively with patients from diverse backgrounds through appropriate knowledge, skills, and attitudes. In oncology practice, this may involve adapting communication, for example, using plain language when discussing chemotherapy side effects or recognising that some patients prefer family-centred decision-making. Such approaches have been associated with improved patient understanding, satisfaction, and trust. However, cultural competence has been criticised for implying that clinicians can fully 'master' another culture and for insufficiently addressing power imbalances.

Cultural humility addresses these limitations by emphasising lifelong learning, self-reflection, and openness to patients' lived experiences. In cancer consultations, clinicians may ask, *"What does this diagnosis mean to you and your family?"* and reflect on how their own assumptions influence communication. This approach is particularly important in areas such as genetic testing or fertility preservation, where cultural values strongly shape decisions.

Cultural safety extends this further by focusing on the impact of clinicians' own cultural identities, assumptions, and power within healthcare relationships. Developed in response to inequities experienced by Indigenous populations, it requires that safety be defined by the patient. In oncology, patients who feel dismissed or misunderstood, for example, in pain management or palliative care, may disengage from services. Cultural safety therefore involves acknowledging past harms, addressing power imbalances, and ensuring care environments feel respectful and inclusive.

4.2

Transcultural care



Case Study 2: Kenji's Dilemma, Genetic Testing and Family Consent

Genetic testing & consent, *differing views on hereditary cancer risk and sharing results within families.* Kenji Sato is a 38-year-old Japanese-American software engineer living in Seattle with his wife, Hana, and their two young children. He was recently diagnosed with stage III colorectal cancer, which came as a shock as there's no known cancer history in his immediate family. His oncologist recommends genetic counselling to explore the possibility of Lynch Syndrome, a hereditary cancer condition that could have implications for his siblings and children.

Kenji's parents immigrated from Japan thirty years ago and maintain strong ties to Japanese cultural values such as "gaman" (endurance), "enryo" (restraint), and "wa" (harmony). Family reputation and privacy are deeply important. Conversations about illness, particularly cancer, are avoided in his family as such topics are considered taboo or shameful. His mother once told him, "Talking about disease invites it into the house."

During a consultation, Kenji listens attentively as the geneticist explains how identifying a mutation could help protect his family. The discussion includes ethical expectations around sharing genetic information with relatives who might also be at risk.

When asked if he would be willing to inform his parents and siblings of the results, Kenji pauses and replies, "In my family, we don't talk about sickness. They believe these things are fate. Hana, his wife, however, insists that they need to know for their children's sake. The tension between collective cultural values and Western biomedical ethics begins to surface. Kenji feels caught between two moral worlds, the duty to his family's privacy and the duty to protect them medically. At their next visit, Kenji appears uneasy. He tells the nurse, **"I've decided not to do the genetic test for now."** He avoids further discussion, and the nurse documents 'patient declined testing.' The oncology team worries that this may delay preventive interventions for the family.

	Key Themes
1	Cultural taboo surrounding cancer and "bad luck" in illness discussions.
2	Conflicting values between family privacy and medical disclosure.
3	Intergenerational differences: Hana (second-generation, Western upbringing) vs. Kenji's parents (traditional, collectivist).
4	Emotional burden of reconciling filial respect with modern ethical expectations.
5	Systemic gap: Lack of culturally adapted genetic counselling resources.

4.2

Transcultural care

Consider the following reflective questions in Amina's Case:

- What specific cultural factors influenced Amina's healthcare experience?
- How could cultural safety and transcultural care principles be incorporated into this consultation?
- What institutional practices (e.g., interpreter access, consultation time) could support clinicians like Dr. Smith?
- How can oncology training incorporate structured learning around these cultural frameworks?
- How can you use self-reflection to improve your cultural humility and communication style when treating patients from different cultural backgrounds?

Consider the following reflective questions in Kenji's Case:

- What cultural factors influence Kenji's hesitation to undergo genetic testing?
- How does the healthcare team's framing of ethical duty impact Kenji's comfort and trust?
- How could the team integrate ethical, cultural, and emotional considerations in a shared decision-making process?
- What role can interdisciplinary support (genetic counselor, social worker) play in culturally safe genetic testing discussions?
- How would you balance respecting patient autonomy with the perceived ethical obligation to inform at-risk relatives?

Transcultural care, based on Madeleine Leininger's theory, emphasises integrating cultural values and practices into care planning. In oncology, this might involve incorporating culturally meaningful dietary practices for patients undergoing chemotherapy, supporting safe traditional remedies, or involving family members in decision-making. For instance, adapting nutritional plans to include familiar foods for patients experiencing treatment-related anorexia can improve intake and wellbeing.

The lack of culturally informed care can negatively affect healthcare outcomes, contributing to poorer communication, longer hospital stays, higher readmission rates, and reduced access to cancer screening and treatment. Although evidence directly linking cultural models to clinical outcomes is still developing, culturally responsive care consistently improves patient trust, engagement, and overall healthcare experience.

Delivering equitable oncology care requires cultural humility, cultural safety, and meaningful system-level change. Achieving this requires ongoing self-reflection and a sustained commitment to addressing structural inequities to improve cancer care outcomes for diverse patient populations.

4.3

Ethnic Disparities in Cancer Outcomes

COMPARATIVE CANCER DISPARITIES IN THE US: INCIDENCE VS. MORTALITY BY ETHNICITY

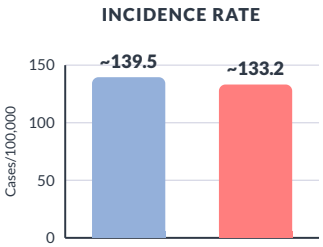
BREAST CANCER

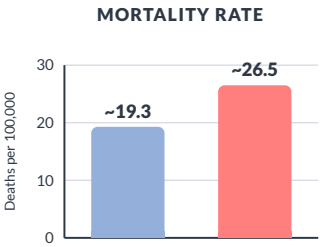




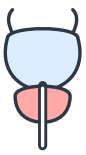
Non-Hispanic White

Black (African American)





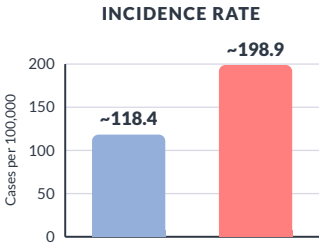
PROSTATE CANCER

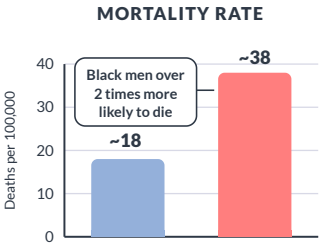




Non-Hispanic White

Black (African American)





CERVICAL CANCER

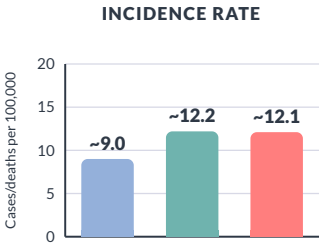


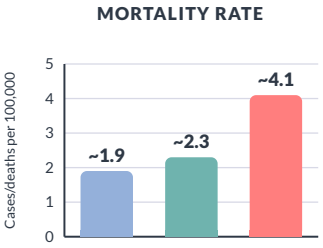


Non-Hispanic White

Hispanic/Latina

Black (African American)





Note:*Data are illustrative examples for specific cancers and groups. Sources for historical trends (e.g., SEER, CDC).

4.3

Ethnic Disparities in Cancer Outcomes

The relationship between ethnicity and cancer is neither simple nor uniform. Across tumour types, income settings, and geographies, one consistent finding emerges: ethnic minority populations are more likely to be diagnosed at a later stage of cancer and more likely to die from it, even when their rates of developing cancer are no higher and sometimes lower than those of the majority population.

Breast cancer illustrates this starkly. In the United States and United Kingdom, Black women are diagnosed with breast cancer at slightly lower rates than white women yet face significantly higher mortality. Part of this reflects tumour biology: triple-negative breast cancer, an aggressive subtype with fewer targeted treatment options, is more prevalent among women of West African descent. But biology does not explain the whole picture. Late presentation, unequal access to mammographic screening, and differences in treatment completion all contribute. For Black men, prostate cancer mortality is more than double that of white men, a disparity that persists even after controlling for stage and treatment.

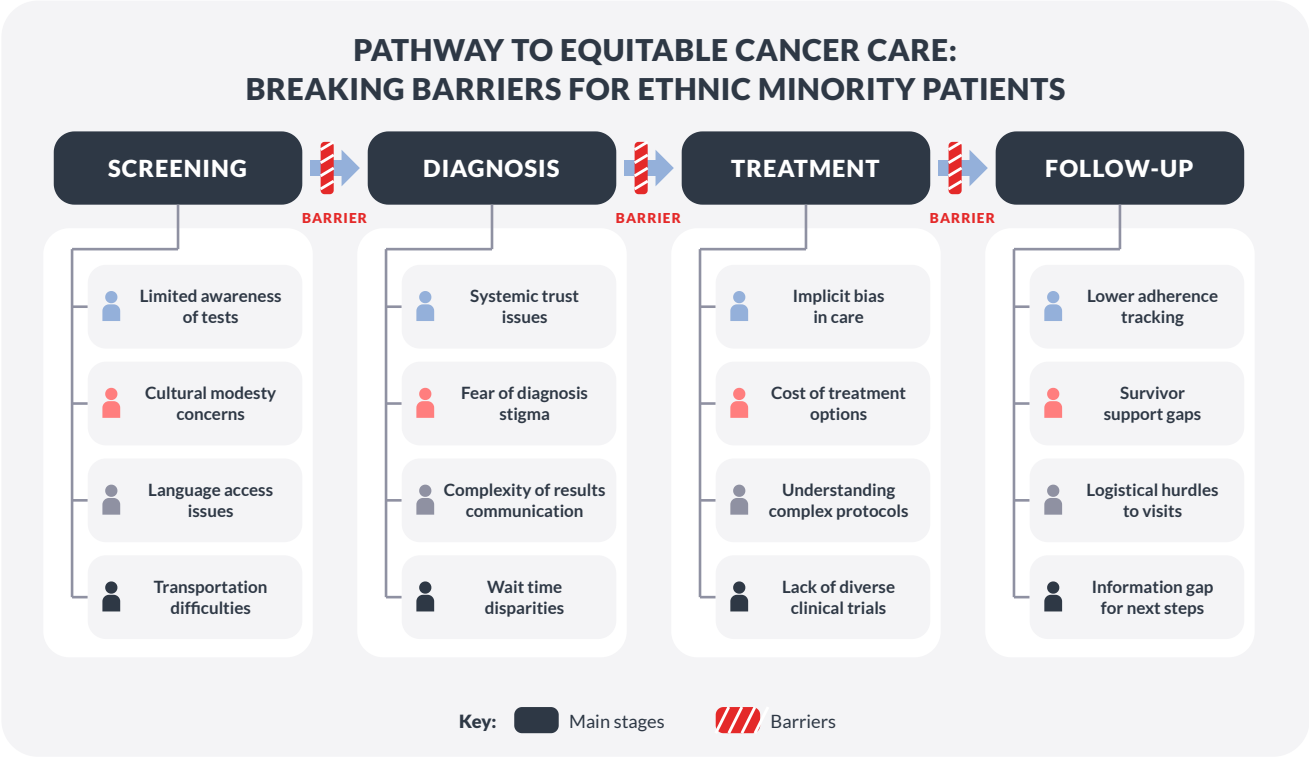
Cervical cancer, largely preventable through vaccination and screening, provides a different lens. In many high-income countries, rates remain disproportionately elevated among Black, South Asian, and migrant women reflecting differential access to vaccination programmes, cultural and linguistic barriers to screening uptake, and historical underinvestment in reaching these communities.

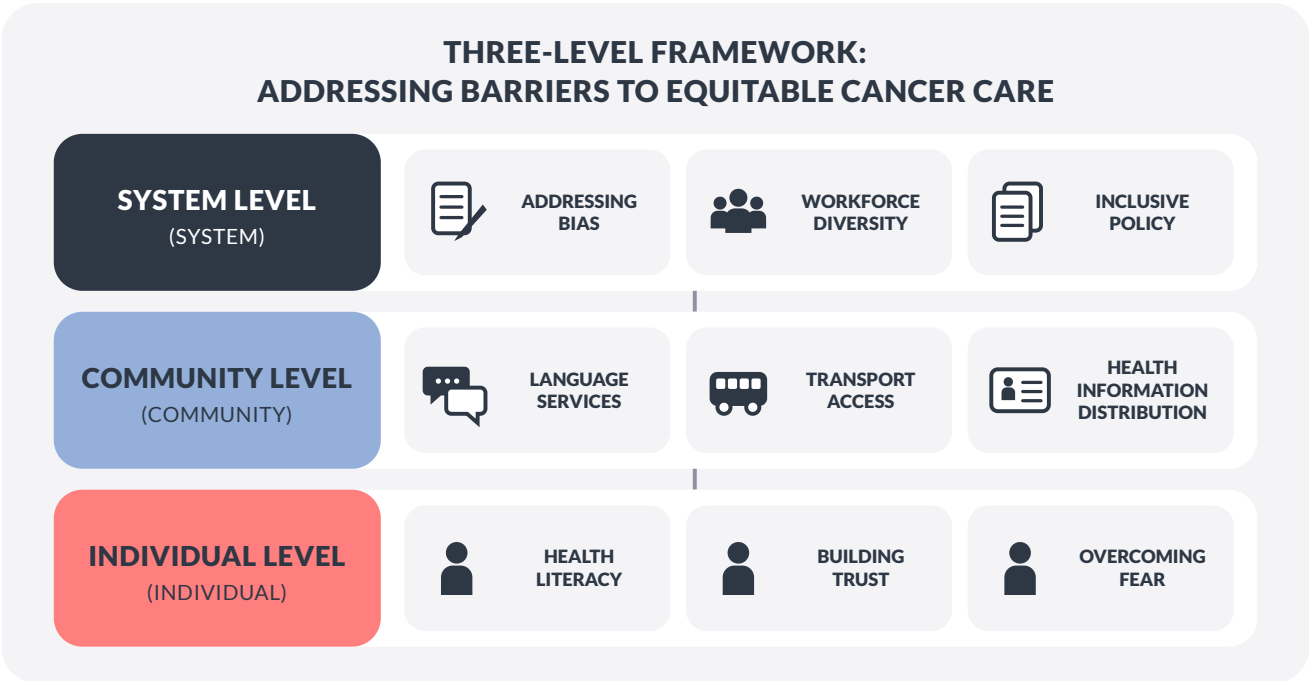
Understanding outcomes requires attending to what happens along the entire cancer pathway: prevention, screening, diagnosis, treatment, and survivorship. Disparities can enter at any stage and compound over time. The same tumour, diagnosed earlier, treated fully, and followed up consistently, produces far better outcomes, yet each of those steps is harder for patients from ethnic minority backgrounds to access equitably.

Disaggregating data matters too. Broad ethnic categories such as Asian or Hispanic encompass highly heterogeneous populations with distinct risks, histories, and relationships with healthcare systems. Meaningful analysis and meaningful change require specificity.

4.4

Barriers to Equitable Cancer Care





4.4

Barriers to Equitable Cancer Care

Disparities in cancer outcomes do not arise by chance. They are produced and perpetuated by a set of identifiable barriers operating at individual, community, and system level that consistently disadvantage patients from ethnic minority backgrounds at every stage of the cancer care pathway.

At the individual and community level, barriers include language, health literacy, fear, fatalism, and medical mistrust. For many ethnic minority communities, historical encounters with healthcare systems have been marked by discrimination, exploitation, or neglect. This legacy from the Tuskegee syphilis experiments to documented differences in pain management and treatment recommendations produces entirely rational wariness that affects engagement with cancer screening and care. Language barriers compound this: patients with limited proficiency in the dominant clinical language receive less information, make decisions with less understanding, and are significantly more likely to be lost to follow-up.

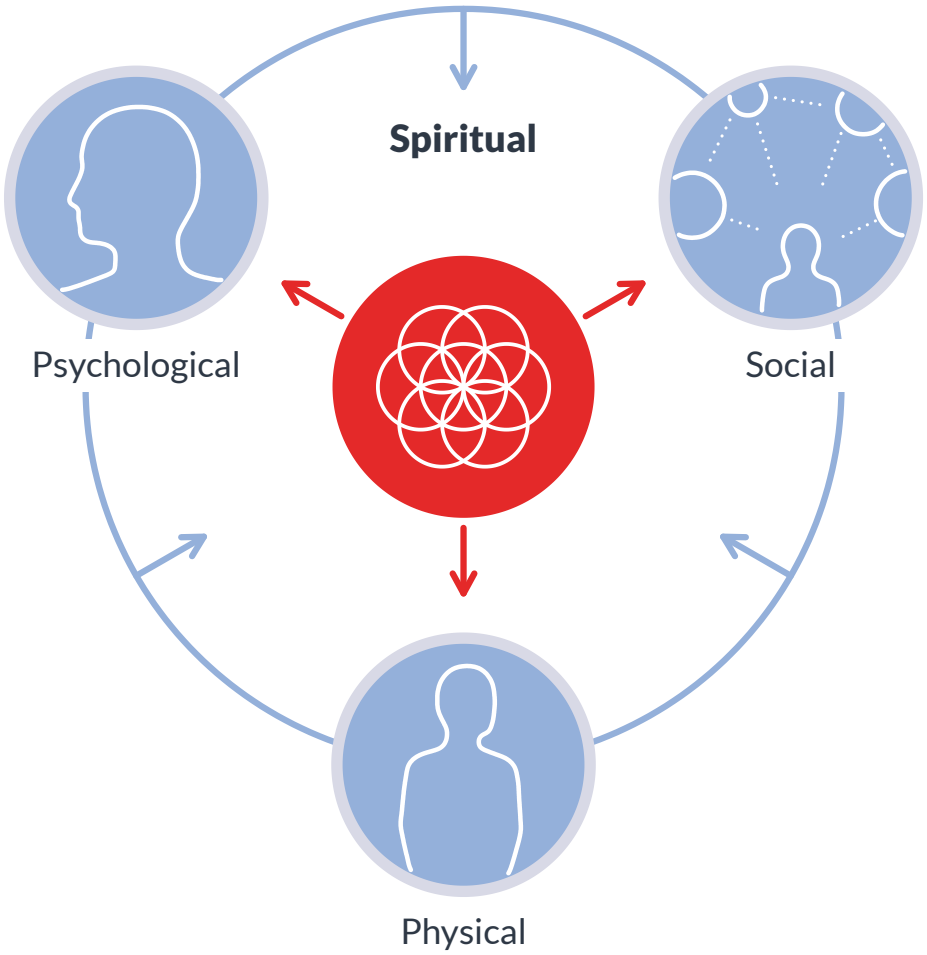
At the system level, structural barriers are equally profound. Insurance gaps and financial costs exclude patients from timely investigation and treatment. Geographic access, the distance from specialist cancer centres disproportionately affects communities of colour in both rural and urban settings. Workforce homogeneity limits the cultural and linguistic concordance that improves patient-provider communication, trust, and adherence. Black and minority ethnic patients are consistently less likely to be referred for genetic testing, offered clinical trial participation, or enrolled in survivorship programmes.

Implicit bias, the automatic associations that influence clinical judgements below conscious awareness operates throughout these encounters. Studies across multiple health systems find that clinicians from all backgrounds make different recommendations based on patient race, even when clinical presentations are identical.

The barriers framework is important because it locates responsibility correctly not with patients, but with systems. Understanding barriers is the precondition for dismantling them: through workforce investment, community partnerships, data collection by ethnicity, and policies that make equitable care the path of least resistance rather than the exception.

4.5

Defining spirituality and spiritual diversity



Spirituality is strongly interrelated with the biopsychosocial dimensions of life. This also means that expressions of spirituality can sometimes be hidden within expressions about physical, psychological and/or social functioning. Figure adjusted with permission from Agora, 2025.

https://www.agora.nl/kennisbank/infographic-zingeving-in-de-palliatieve-zorg/

4.5

Defining spirituality and spiritual diversity

The taskforce Spiritual Care of the European Association of Palliative Care has defined spirituality as “the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.”. It is, thus, a multidimensional construct that encompasses:

- Existential questions: How people understand themselves, others and the world.
- Values: What people find most important in life.
- Religious beliefs and practices: How people relate to the sacred or ultimate.

In many countries, spirituality, religion and culture are difficult to separate. Here, religious beliefs and practices are guiding principles in both public and private life. In other countries, spirituality, religion and culture are more separate. Here, spirituality and religion are often considered matters of the private sphere, whereas the public sphere and national culture are considered ‘secular’. In these secularized countries, spirituality and religion are also often considered related, but separate. Religion then refers to institutionalized beliefs and practices around the sacred, whereas spirituality refers to subjective experiences of the sacred and more personalized forms of practice that combine elements of various religions, spiritual movements, and cultures.

It is important to consider spirituality in clinical practice, because of its positive relationship to both physical and mental health. This can be explained, among others, through lifestyle regulations, social and material support, and stress regulation. On the other hand, spiritual beliefs can also negatively influence treatment decisions and spiritual distress is negatively associated with health.

The Figure shows that spirituality influences how people experience their physical, psychological and social lives, because it reflects the values that they attach to these areas. Conversely, physical, psychological and social abilities influence how spirituality can be experienced. For example, illness can limit work or family roles, which may cause feelings of loss and grief over ones identity and sense of connectedness. This interrelationship between the dimensions of functioning also means that the spiritual dimension can be hidden within expressions about the physical, psychological or social state of the person.

4.6

Centering spirituality in care

The Dutch clinical guideline Existential and spiritual aspects in palliative care (2018) distinguishes between three levels of spiritual care:

What	Who	How
Attention	Everybody	Have a person-centered approach through being attentive to the person and their biography
Accompaniment	All care professionals and volunteers who have received spiritual care training	Talk about meaning, purpose, and the way the person connects to the moment, to self, to others, to nature, to the significant and/or the sacred. Use non-verbal methods such as mindfulness moments, music or small rituals if appropriate.
Crisis or complex care	Specialist spiritual care professionals, such as chaplains or grief counsellors	Use therapeutic skills to work through spiritual needs and/or crisis.

4.6

Centering spirituality in care

Research has shown that patients appreciate attention to religion and spirituality in clinical practice, because it influences their experience of health and treatment decisions. It is, therefore, advised that all people dealing with patients, from clinical to support staff, pay attention to patients' spirituality. Taking a person-centered approach in work already meets spiritual needs of patients, for example by showing interest in who the person is and adjusting treatment to the needs and habits of the patient. This approach meets everyday spiritual needs such as feeling connected, experiencing a positive identity, and experiencing purpose and comprehension in life. Some patients express spiritual needs that require more specific attention. Here, a form of accompaniment of the patient in their spirituality is needed. Screening tools, such as the ones below, can assist in both recognizing spiritual needs and talking about them.

MVCN questions:

- How do you make sense of what is happening to you?
- What sources of strength do you look to when life is difficult?
- Would you find it helpful to talk to someone who could help you explore the issues of spirituality/faith?

FICA:

F – Faith, Belief, Meaning: "Do you consider yourself to be spiritual?" or "Is spirituality something important to you?" "Do you have spiritual beliefs, practices, or values that help you to cope with stress, difficult times, or what you are going through right now?" "What gives your life meaning?"

I – Importance and Influence: "What importance does spirituality have in your life?" "Has your spirituality (or sources of meaning) influenced how you take care of yourself, particularly regarding your health?" "Does your spirituality affect your healthcare decision making?"

C – Community: "Are you part of a spiritual community?" "Is your community of support to you and how?" "Is there a group of people you really love or who are important to you?"

A – Address/Action in Care: "How would you like me, as your healthcare provider, to address spiritual issues in your healthcare?"

In case spiritual needs require specialist attention or there are other reasons why care professionals cannot attend to the needs themselves, it is advised to refer to a chaplain or, for example, a grief counsellor.

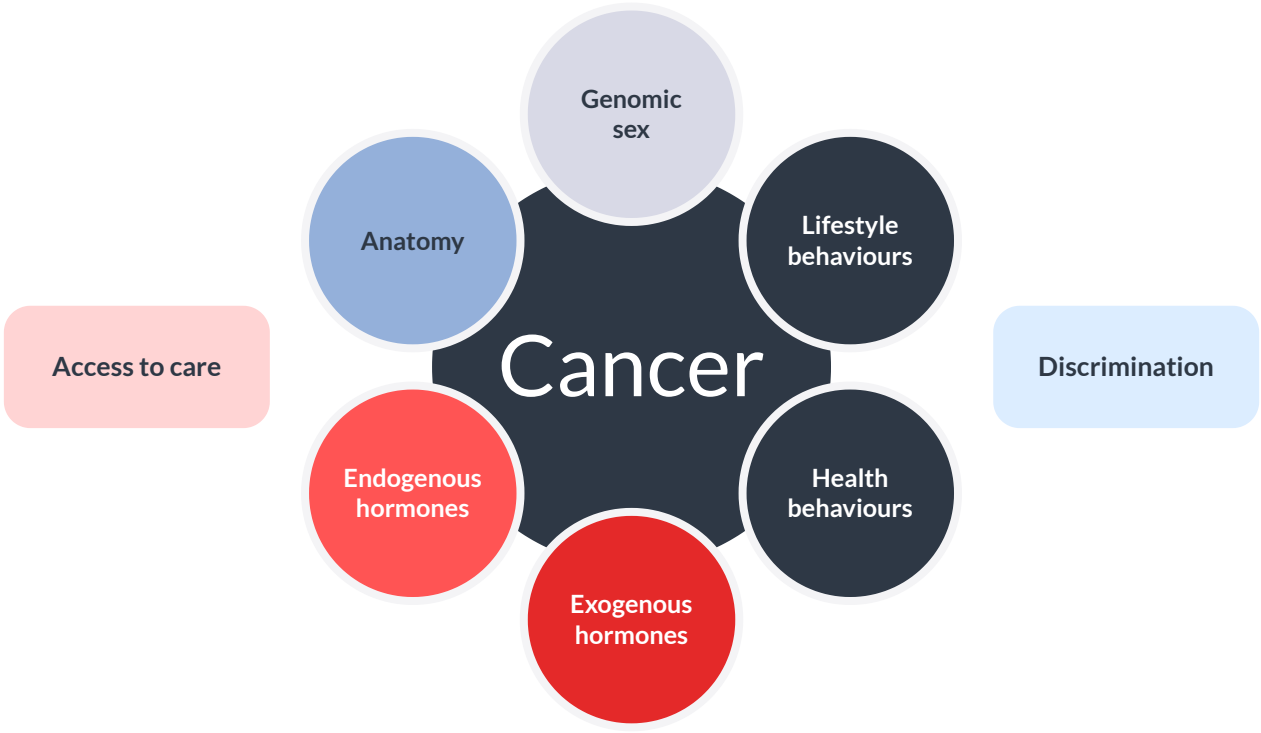
It is important to document what has been learned about spiritual needs and resources in the patient records and integrate it into treatment plans.

4.7

Gender Diversity: Sex and gender influence cancer risk and management

Examples of Sex Characteristics	Examples of Gender Characteristics
Sex chromosomes	Gender identity - The gender with which a person identifies.
Gene expression	Gender expression - How a person outwardly presents themselves in relation to gendered forces.
Hormone profile	Perceived or presumed gender - How a person's gender is typically understood by those around them, which may differ from their gender identity and/or gender expression.
Secondary sex characteristics	Gender modality - Whether a person's gender identity is the same as their sex assigned at birth (the person is cisgender) or not (the person is transgender).
Internal reproductive organs	
External reproductive organs	

List and definitions adapted from MESSAGE Project Policy Toolkit (https://www.messageproject.co.uk/wp-content/uploads/2025/08/Funders-Toolkit.pdf)



Reflection Prompts on Gender

Where do you see gender differences in your practice?

What are the gender norms, expectations and stereotypes in your country/culture?

How might these lead you to make assumptions?

Where might you need to enquire further about patient preferences and needs?

4.7

Gender Diversity: Sex and gender influence cancer risk and management

Sex refers to the biological attributes that differentiate females and males. Gender refers aspects of a person's identity which may be masculine, feminine, both, neither or third gender. People experience social constraints and privileges based on gender, which may influence behaviours, self-perception and treatment. Gender is experienced in diverse ways across time and culture.

There are clear differences in cancer risk and outcomes between cisgender men and women. Men have a high incidence and mortality across most cancers. For some types, risk is clearly associated with sex characteristics. For example, breast cancer is far more common in females due to breast tissue volume and exposure to oestrogen and progesterone. For some time it was assumed that in most cancers, differences were observed due to gendered lifestyle behaviours (e.g. smoking) influenced by gender, culture and other factors. Recent studies demonstrate influences of sex and gender in cancer incidence and mortality. Evidence is also emerging for the role of gender in treatment decision making, affecting clinical outcomes.

In general, women prioritise quality of life and minimising side effects when selecting cancer treatments. In one study, some women with gastroesophageal cancer were more likely to decline chemotherapy. These differences resulted in lower overall survival. Women are also more likely to report side effects from anti-cancer therapies, though this may be due to physiological differences associated with sex, leading to over-dosing. Women also report their side-effects being taken less seriously, which may impact outcomes.

Studies on treatment selection may not discern whether gendered treatment differences result from patient choice or physician bias, with the latter being observed according to both gender and ethnicity. In the above study of gastroesophageal cancer, the authors hypothesised that treatment differences were the result of more single older women in the population, with care teams assuming these women had inadequate social support to undertake anti-cancer therapy.

Women with cancer report more supportive care needs, higher levels of anxiety and depression, and greater reliance spirituality for support. It is unclear to what degree these findings in themselves reflect a reporting bias, as women are known to display greater healthcare seeking behaviours.

These are gendered trends but will vary by culture, geography and between individuals.

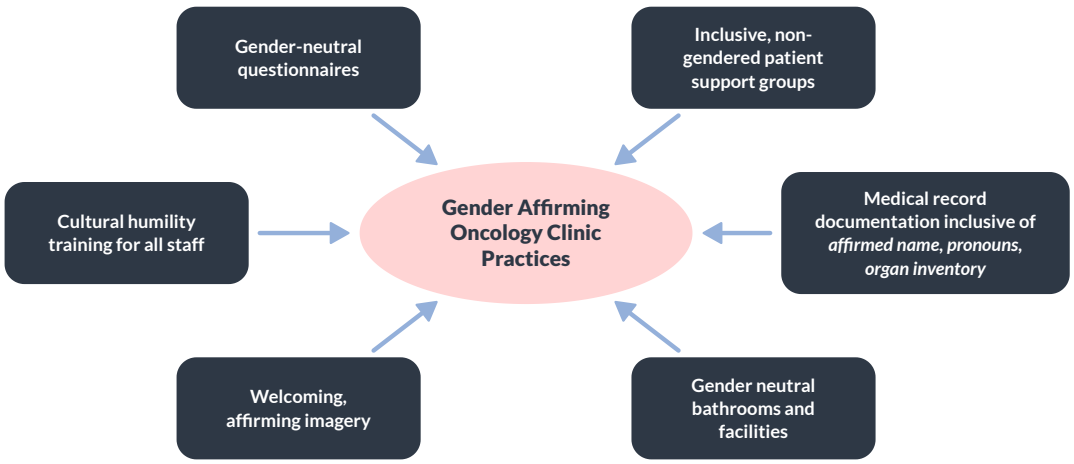
4.8

Care for Trans and Gender Diverse People with Cancer

Useful Terminology for Working With Gender Diverse Communities

Term	Definition
Gender diverse	An umbrella term for the range of gender identities and expressions that differ from traditional gender norms, including transgender non-binary, genderqueer, genderfluid, and agender identities.
Trans woman	Someone who identifies as female but was assigned male at birth.
Trans man	Someone who identifies as male but was assigned female at birth.
Non-binary person	Someone who identifies as neither masculine nor feminine exclusively.
Gender incongruence	The experience of a person when their gender identity is different to the sex they were assigned at birth.
Gender dysphoria	Psychological and physiological discomfort or distress caused by a discrepancy between a person's gender identity, their sex assigned at birth, and their primary/secondary sex characteristics.

Affirming Care Practices for Gender Diverse People in the Oncology Clinic



From: Cathcart-Rake EJ, et al. CA Cancer J Clin. 2025. doi: 10.3322/caac.21872.

Reflection Prompts on Trans and Gender Diverse People

What are the laws and attitudes to being transgender or gender diverse where you are?

What is the attitude to gender non-conformity in your culture?

What assumptions do you have about gender diverse people and their care?

How does your organisation and team cater to the needs of gender diverse people?

4.8

Care for Trans and Gender Diverse People with Cancer

An estimated 0.3–1% of the population identify as TGD. As gender modality is not routinely collected in healthcare data, cancer incidence and outcomes data are limited. However, studies demonstrate clear differences in cancer risk and treatment, including:

- Reduced health-seeking behaviours linked to stigma and healthcare mistrust,
- Risk factors resulting from minority stress such as smoking and alcohol,
- Changes in anatomy and hormones related to gender-affirming care,
- Healthcare professionals' lack of knowledge, assumptions or discrimination leading to lower screening and diagnostic overshadowing.

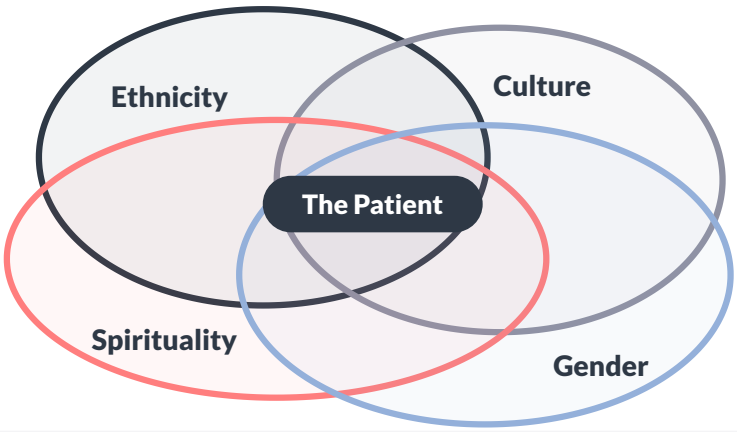
For many TGD people, gender-affirming hormone therapy (GAHT) improves wellbeing, mental health and quality of life. GAHT can affect cancer risk, detection and treatment. In most cases, trans people will accept cancer risks equivalent to those of a cisgender person of the same gender. Transgender women receiving oestrogen develop breast tissue and have elevated breast cancer risk compared to cisgender men, though current data do not show equivalence with cisgender women's rates. Prostate cancer risk is lowered. Transgender men have a reduced breast cancer risk compared to cisgender women but higher cisgender men. They retain risk for gynaecological cancers unless the relevant organs have been removed. Provider and system barriers, and gender dysphoria, may result in lack of access to screening.

GAHT can complicate treatment in hormone-responsive cancers. Oestrogen receptor-positive breast cancer in a transgender woman raises the question of whether to continue GAHT. Stopping oestrogen has significant psychological and physical consequences but continuation may risk recurrence or progression. In transgender men, endocrine therapy must be tailored due to conversion of testosterone to oestradiol. TGD people frequently prioritise GAHT over cancer care due to its positive effects, and shared decision-making is essential.

For many TGD patients, there will be no intersections between their cancer and gender-affirming care. The priority is an affirming experience. In 2025, the Multinational Association of Supportive Care in Cancer published recommendations for inclusive cancer care in TGD people. These include use of correct name and pronouns, inclusive and gender-neutral information and spaces, and use of preferred language for gendered body parts. Ultimately, a non-assumptive approach and cultural humility are key.

4.9

Intersectionality and The Whole-Person Care



ETHNICITY

- Disparities
- Barriers
- Structural racism
- Late diagnosis

CULTURE

- Beliefs
- Stigma
- Family roles
- Treatment decisions

SPIRITUALITY

- Meaning
- Coping
- Religious practice
- End of life

GENDER

- Identity
- Bias
- Transgender care
- Side effect reporting

THE PRINCIPLE

"No single dimension of identity captures the full complexity of a person's experience of cancer care"

4.9

Intersectionality and The Whole-Person Care

The chapters in this section have examined four dimensions of diversity in cancer care: ethnicity, culture, spirituality, and gender. Each provides an important analytic lens; however, considered collectively, they demonstrate that no single aspect of identity can adequately explain an individual's experience of illness or their engagement with healthcare systems.

Intersectionality, first articulated by Kimberlé Crenshaw in 1989, offers a framework for understanding how overlapping social identities produce forms of disadvantage that cannot be fully understood in isolation. Within oncology, this perspective is particularly salient. For example, a South Asian Muslim woman receiving chemotherapy may experience cancer stigma, family-centred decision-making, religious coping, and trust in healthcare as interconnected rather than discrete concerns. These dimensions interact with structural features of healthcare and may either compound inequity or be mitigated through responsive clinical practice.

The cases discussed in earlier chapters illustrate this complexity. Amina's hesitation about chemotherapy cannot be attributed solely to culture; it is also shaped by language, gendered dynamics, community narratives about cancer, and limited opportunities for dialogue within the consultation. Similarly, Kenji's reluctance to pursue genetic testing reflects both cultural values and inadequate access to culturally adapted counselling. A transgender woman seeking breast cancer screening may encounter barriers associated with gender identity, which intersect with other social positions and healthcare experiences.

The implication for practice is not that clinicians must possess exhaustive expertise in every identity category, but that they should approach patients with critical curiosity, reflexivity, and openness. Cultural humility, spiritual assessment, affirming care for gender-diverse patients, and awareness of ethnic disparities all require clinicians to ask, listen, and adapt while recognising how power operates within clinical encounters. Accordingly, diversity in cancer care should not be treated as a checklist of discrete characteristics. Rather, it requires sustained attention to the whole person and to the social and structural conditions that shape their experience of care.

CHAPTER 5

05

Supportive Care: What Is It?

Marina Nelia Rosanu, Fedro Alessandro Peccatori, Daniele Carrieri

IN THIS CHAPTER

5.1 What is supportive care?
5.2 A holistic understanding of the patient
5.3 Beyond symptoms: the work of living with cancer
5.4 Why is it difficult to implement supportive care in clinical practice?
5.5 From principles to practice: making supportive care happen

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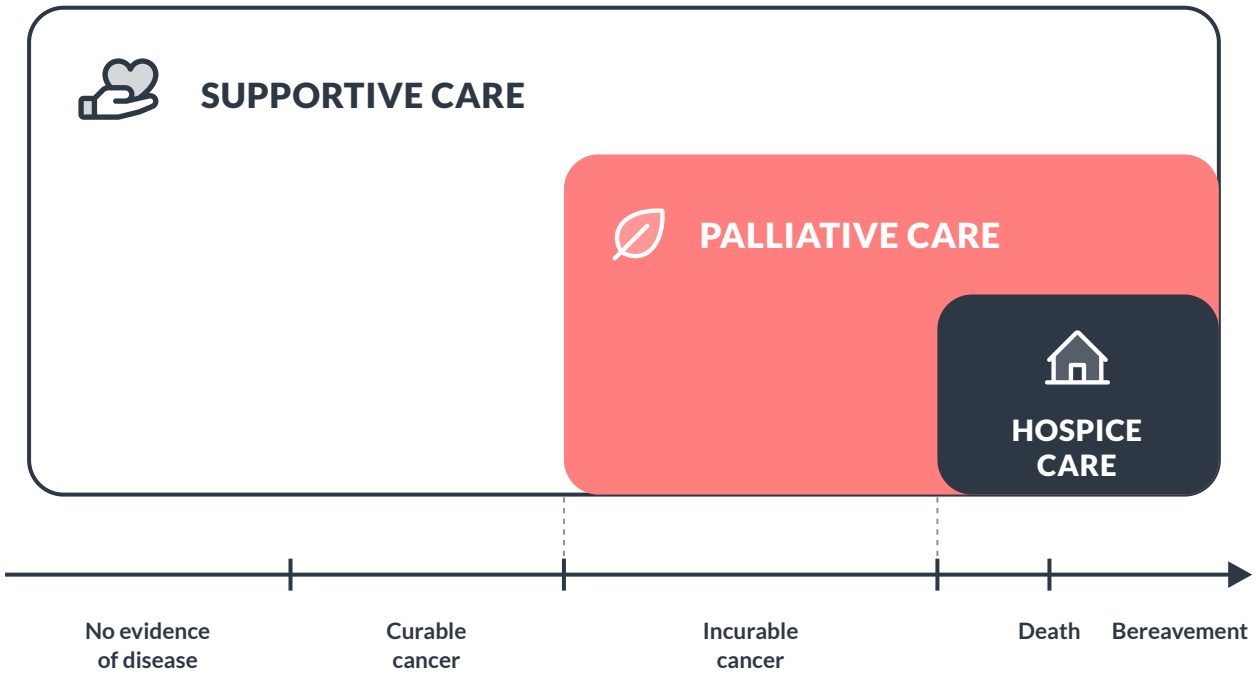
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5.1

What is supportive care?

Supportive care:

- Includes prevention and management of cancer and treatment-related toxicity
- Covers the entire cancer journey
- Extends beyond symptom control
- Includes survivorship and end-of-life care
- Integrates physical, psychological, social and existential dimensions
- Encompasses palliative and hospice care



Conceptual framework for supportive care, palliative and hospice care (adapted from Hui and Bruera, 2016)

5.1

What is supportive care?

Supportive care is a fundamental component of oncology, yet it remains one of its most frequently misunderstood concepts. Many clinicians and patients still associate supportive care primarily with symptom control in advanced disease or view it as synonymous with palliative care. However, its role extends far beyond this.

The Multinational Association of Supportive Care in Cancer (MASCC) defines supportive care as the prevention and management of the adverse effects of cancer and its treatment across the entire cancer continuum. This includes physical and psychological symptoms, treatment-related toxicities, rehabilitation, survivorship issues, and end-of-life care. Importantly, supportive care is not limited to patients with incurable disease. It begins at diagnosis and accompanies patients throughout treatment, survivorship, recurrence, and advanced illness, while also addressing the needs of families and caregivers.

Within this framework, palliative care and hospice care are not separate entities but components of supportive care. Palliative care focuses on improving quality of life for patients living with serious illness and should be integrated early alongside disease-directed therapies. Hospice care represents a more specialised model for patients approaching the end of life. Understanding these relationships helps overcome the misconception that supportive care becomes relevant only when curative options are exhausted.

As cancer treatments become increasingly effective and complex, supportive care has become more important than ever. Patients now live longer with cancer and experience a growing range of treatment-related toxicities, survivorship challenges, and psychosocial needs.

This evolution is reflected in international initiatives such as the Supportive Care 2030 movement, which identifies supportive care as a cornerstone of patient-centred cancer care. Similarly, European Society for Medical Oncology (ESMO), National Comprehensive Cancer Network (NCCN), and other professional organisations have developed extensive supportive care recommendations addressing symptom management, treatment toxicity, survivorship, rehabilitation, communication, psychological wellbeing, and palliative care integration.

Ultimately, supportive care is not defined by a specific intervention, profession, or stage of disease. Rather, it is an approach to oncology that seeks to anticipate needs, prevent avoidable suffering, and optimise quality of life and delivery of care throughout the cancer journey. In this sense, supportive care is not an optional addition to treatment, but an essential part of treatment itself.

5.2

A holistic understanding of the patient



5.2

A holistic understanding of the patient

A holistic approach is a core principle of supportive care, recognizing the need to address the whole person and the relationships that shape their wellbeing, not just the disease. Cancer is not experienced solely as a biological condition, but as a life event that affects multiple dimensions. Consequently, supportive care requires clinicians to look beyond diagnosis and treatment and consider the broader impact of illness on patients and their families.

Alongside physical symptoms and treatment-related toxicities, patients commonly experience psychological distress, uncertainty, changes in social roles, difficulties maintaining work and daily activities, financial pressures, concerns regarding sexuality and fertility, and questions about meaning, identity and the future. These issues may be as important to patients as the disease itself and frequently influence their overall experience of care.

Importantly, these dimensions are closely interconnected. Physical symptoms can contribute to emotional distress, psychological difficulties may affect treatment adherence, and social or financial challenges can influence quality of life and functional recovery. Understanding these interactions is essential for identifying needs that may otherwise remain overlooked.

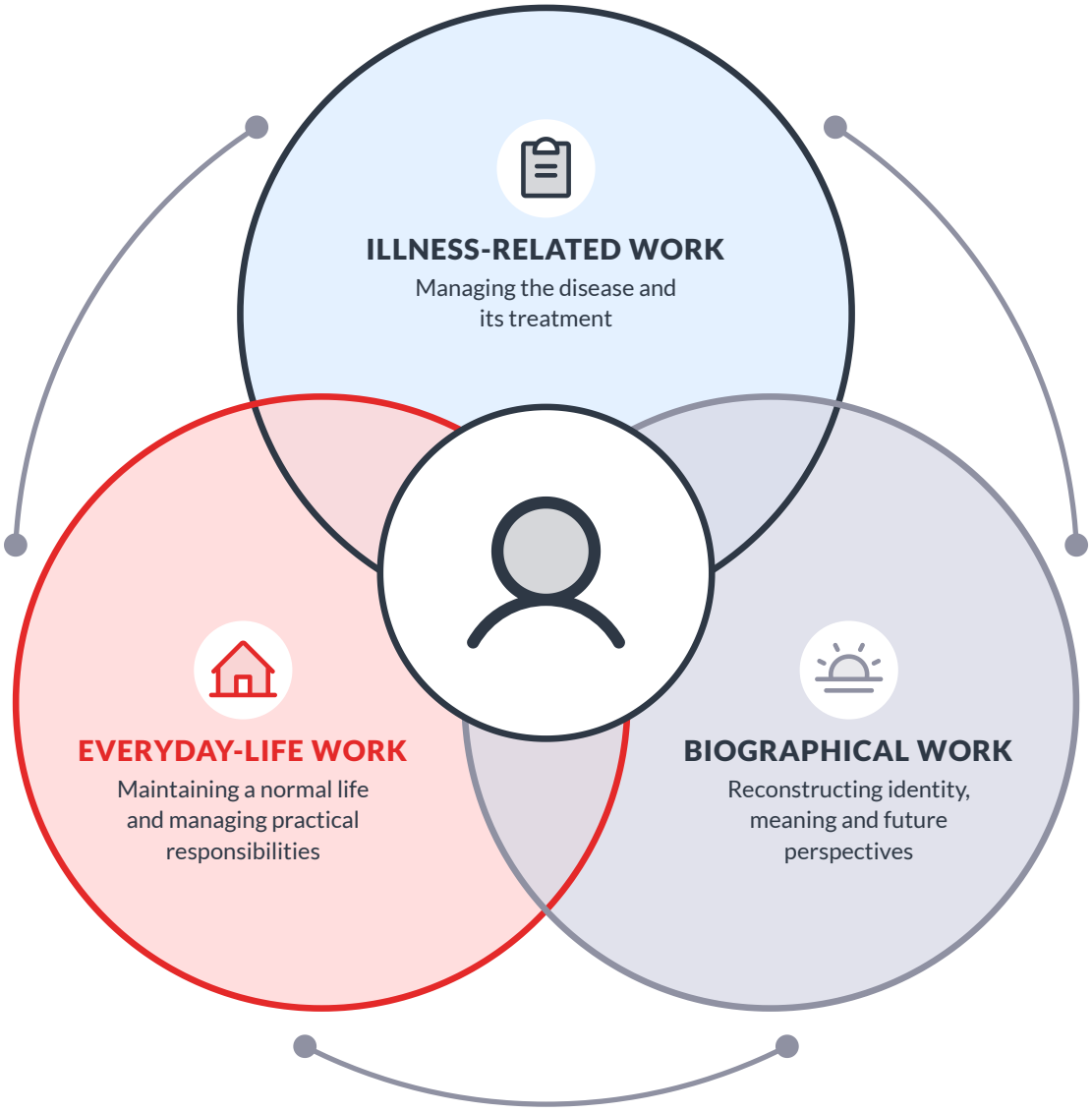
A holistic perspective also recognises that cancer affects not only individuals but their entire support networks. Family members and informal caregivers often experience emotional, practical and financial burdens while helping patients navigate the disease. Their wellbeing can directly influence the patient's ability to cope with treatment and daily life.

This broader, relational understanding of health is increasingly reflected in international supportive care recommendations. NCCN guidelines advocate routine assessment of symptoms, distress, psychosocial concerns and functional status, while ESMO survivorship recommendations emphasise the long-term physical, psychological, social and occupational consequences of cancer and its treatment.

Because many of these concerns may not be evident during routine consultations, regular systematic assessment is essential. Engaging patients and their networks in designing meaningful tools, such as patient-reported outcome measures (PROMs) and experiences measures (PREMs), can provide a structured way to understand symptoms, functional limitations, emotional wellbeing, social concerns and quality of life directly from patients. By making these experiences visible, PROMs and PREMs can help identify unmet needs and support more personalised and responsive supportive care.

5.3

Beyond symptoms: the work of living with cancer



Three types of work. One person. Many connections.

5.3

Beyond symptoms: the work of living with cancer

A holistic understanding of the patient requires understanding the work patients undertake every day to live with the disease. Research has identified three interconnected domains of work performed by people living with cancer: illness-related work, everyday-life work and biographical work.

Illness-related work refers to the tasks associated with managing the disease and its treatment. Patients must understand complex medical information, make decisions about treatment options, attend multiple appointments, monitor symptoms, manage medications and adapt to treatment-related toxicities. Access to clear and timely information remains among the most frequently reported unmet needs across the cancer continuum, particularly regarding treatment effectiveness, side effects, risk of recurrence and symptom management.

Everyday-life work encompasses the effort required to maintain daily functioning despite illness. Patients continue to fulfil family responsibilities, maintain relationships, work, study and manage practical or financial obligations. Balancing treatment demands with everyday life often represents a substantial burden. Contemporary survivorship recommendations increasingly recognise employment, financial wellbeing, physical functioning and social participation as important outcomes of cancer care.

Biographical work describes the process of adapting one's sense of self and future to the reality of illness. Cancer can disrupt personal goals, life plans and expectations, requiring patients to reconstruct meaning, identity and priorities in the face of uncertainty.

These forms of work are closely interconnected. Difficulties in one domain frequently affect the others. Treatment-related fatigue may compromise employment and social participation, while practical or financial challenges may increase emotional distress and reduce engagement with care.

Recognising and systematically assessing the work involved in living with cancer helps transform supportive care from a reactive response to problems into a proactive strategy aimed at maintaining function, autonomy and participation throughout the cancer journey.

5.4

Why is it difficult to implement supportive care in clinical practice?



5.4

Why is it difficult to implement supportive care in clinical practice?

Despite being recognised as a fundamental component of high-quality oncology, supportive care remains inconsistently implemented in routine practice. The challenge is a combination of cultural, professional, organisational and systemic barriers.

A first barrier is cultural. Oncology has traditionally been organised around diagnosis, treatment response and survival. Within this disease-centred model, supportive care may be perceived as secondary to cancer treatment or relevant only in advanced stages of disease. This misconception persists despite international recommendations emphasising that supportive care should be integrated throughout the entire cancer continuum.

Professional barriers also play an important role. Many supportive care needs remain invisible unless actively explored. Patients may hesitate to discuss emotional, social, financial or sexual concerns, while healthcare professionals often receive limited training in addressing these issues. Time constraints and increasing clinical complexity further reduce opportunities to identify unmet needs and provide comprehensive support.

Implementation is also challenged by organisational factors. Effective supportive care requires coordination among oncologists, nurses, psychologists, rehabilitation specialists, nutritionists, social workers and palliative care teams. However, these services are frequently fragmented, resulting in delayed referrals, inconsistent follow-up and unmet patient needs.

Workforce pressures further complicate delivery. Increasing patient volumes, administrative burden and organisational pressures are leading to professional burnout, limiting the capacity of healthcare teams to provide proactive, person-centred care.

Finally, access to and delivery of supportive care remains highly variable within and across healthcare systems. Psychological support, rehabilitation, survivorship programmes, nutritional counselling, palliative care and caregiver services are not universally available and may differ according to institution, region or national policies. Even within publicly funded healthcare systems, access may depend on local resources, reimbursement mechanisms or patients' ability to navigate complex care pathways.

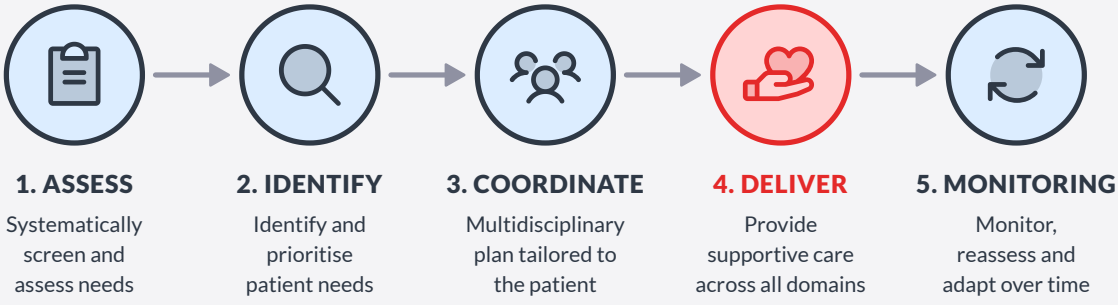
The challenge is therefore not only to recognise the value of supportive care, but to ensure that healthcare systems, services and clinical pathways are designed to deliver it consistently, equitably and at the right time for every patient.

5.5

From principles to practice: making supportive care happen

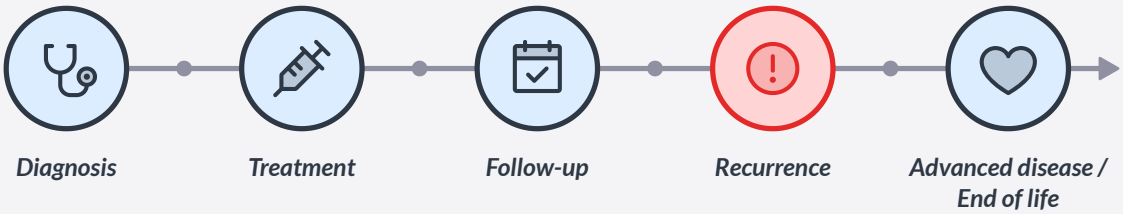
WHAT?

Practical approach



WHEN?

At every stage of the cancer journey



WHY?

To achieve better outcomes



5.5

From principles to practice: making supportive care happen

The challenge is no longer determining whether supportive care is important, but how to ensure that every patient receives it consistently and at the right time. Recent recommendations from MASCC, ESMO, NCCN and the Supportive Care 2030 initiative converge on several practical principles for implementation.

First, supportive care should be proactive rather than reactive. Waiting for patients to report problems often results in delayed recognition of symptoms, distress and unmet needs. Routine screening and regular assessment throughout the cancer pathway allow concerns to be identified before they become crises. Equally important is early integration and continuous adaptation of supportive care, as patient needs change across diagnosis, treatment, follow-up, recurrence and advanced disease.

Second, supportive care should extend beyond physical symptoms alone. Effective assessment includes emotional wellbeing, functional status, social circumstances, caregiver burden, financial concerns and survivorship needs. Understanding these dimensions provides a more complete picture of the patient's experience and helps guide appropriate interventions.

Third, supportive care requires multidisciplinary collaboration. No single healthcare professional can address the full spectrum of patient needs. Oncologists, nurses, psychologists, rehabilitation specialists, nutritionists, social workers, palliative care teams and primary care providers all contribute to supportive care. Clear referral pathways and effective communication between services are therefore essential. Consequently, the availability and integration of supportive care services should be regarded as a key indicator of quality in cancer care.

Most importantly, supportive care is increasingly recognised as a determinant of optimal cancer treatment. By maintaining functional status, reducing treatment-related burden and supporting adherence, it helps patients remain fit for therapy and maximise the benefits of modern oncologic treatments. Nevertheless, these outcomes are often more difficult to measure than traditional oncologic endpoints such as response or survival, which may contribute to lower prioritisation in clinical practice and healthcare planning.

Looking forward, supportive care will increasingly require collaboration beyond healthcare services alone. Families, caregivers, patient organisations and local communities play an essential role in addressing social isolation, practical support needs and bereavement. Emerging public health models such as compassionate communities recognise that many challenges associated with equitable and excellent cancer care, including good quality of life and death, cannot be addressed by healthcare professionals alone and highlight the value of stronger links between healthcare systems and community resources.

Ultimately, supportive care translates the principles of person-centred oncology into clinical practice, ensuring that advances in cancer treatment translate not only into longer survival, but also into better lives for patients and their families.

CHAPTER 6

06

Why oncologists should know some ethics?

Giovanni Boniolo

IN THIS CHAPTER

6.1 What is ethics?
6.2 What should be avoided?
6.3 How to structure an ethical position?
6.4 Oncologists' ethical problems
6.5 Patients' Ethical/Existential Problems
6.6 What is the ethical/existential counselling?
6.7 Ethics in Clinical Oncology – Take Home Messages

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6.1

What is ethics?

Ethics concerns the judgment, in terms of blameworthy or praiseworthy, of human actions or omissions



That is, it deals with human actions already done or to be done

That is, applied ethics has nothing to do with

- **Law**
- **Religion**
- **Moral prejudices**

6.1

What is ethics?

Ethics is the systematic evaluation of human actions or omissions in terms of whether they are **praiseworthy or blameworthy**. It is fundamentally concerned with human conduct, both **past actions** and those that are **yet to be performed**. In this sense, ethics provides a framework for critically assessing not only what people do but also **what they ought to do**, guiding **moral reflection** and **responsible decision-making**. It helps individuals and societies determine the principles that should govern behavior, offering tools for reasoning about right and wrong beyond mere instinct, habit, or convention.

Within the field of **clinical ethics**, a frequent and significant error is attempting to resolve ethical problems using frameworks that are **not intrinsic to ethical reasoning**. Specifically, ethical questions in clinical contexts are sometimes addressed through appeals to **law**, **religion**, or **personal moral prejudices**. While these frameworks may influence ethical perception, they are **insufficient for rigorous moral evaluation**. Applied ethics must therefore be clearly distinguished from these domains to maintain the integrity of ethical analysis.

Law and **religion** are normative systems with distinct sources of authority and methods of justification. Legal reasoning relies on **codified rules**, **institutional norms**, and **enforceable obligations**, whereas religious reasoning draws legitimacy from **theological doctrines** and **spiritual traditions**. Although these systems can intersect with ethical considerations and inform ethical deliberation, they **cannot substitute for ethical analysis itself**, as their primary objectives and methods differ from the critical evaluation of moral responsibility.

Similarly, **personal moral prejudices** are inadequate foundations for ethical reasoning. They often reflect **socially inherited** or **culturally ingrained assumptions** rather than principles subjected to **systematic reflection** and **critical scrutiny**. Relying on unexamined biases can lead to **inconsistent, subjective, or unjustifiable moral judgments**, which undermine the purpose of applied ethics.

For these reasons, applied ethics, especially in **clinical contexts**, demands **systematic, critical, and reflective reasoning**. Ethical deliberation must remain **independent from legal mandates, religious authority, and unreflective personal beliefs**. It relies on **careful argumentation**, **explicit justification**, and the **thoughtful evaluation** of human actions under analysis.

By emphasizing **rational reflection and principled judgment**, ethics ensures that decisions regarding patient care and professional conduct are both morally defensible and aligned with fundamental human values

6.2

What should be avoided?



Do not trust someone's moral common sense

If you had a severe cardiovascular disease, would you look for a "cardiovascular" amateur? Someone with a "cardiovascular" *common sense*?

Why should you be confident in the moral *common sense* of an ethical amateur?

DOC, WHAT WOULD YOU DO IN MY SHOES?

Do not be a moral paternalist

Oncologists must not solve patients' moral/existential problems based on their own idea of what is good and what is bad.

Patients and oncologists have and live in different shoes!

6.2

What should be avoided?

In **clinical ethics**, it is essential to identify practices that must be avoided when addressing **moral issues** in medical care. Ethical reflection in oncology requires **professional competence**, and failing to respect this can compromise **patient autonomy**, **well-being**, and **trust in the clinician**.

A particularly dangerous error is relying on one's so-called **"moral common sense."** Such judgments are often shaped by **personal intuition**, **cultural habits**, or **unexamined assumptions** rather than careful ethical analysis. Treating **moral common sense** as sufficient can be **misleading, arbitrary, and potentially harmful**, because what feels **obvious** to an individual may ignore the patient's **values**, **context**, or **vulnerability**. In **oncology**, where the stakes are high, relying on common sense risks turning serious ethical decisions into **amateur judgments** rather than **professional moral reasoning**. We need **persons trained in ethical principles, reasoning, and reflection, n**ot reliance on intuition or gut feeling, to navigate **complex situations responsibly**.

Another practice to avoid is **moral paternalism**, in which clinicians attempt to resolve a patient's **moral or existential questions** according to their own beliefs about what is right or wrong. In doing so, the clinician **imposes personal values** and overrides the patient's perspective. This is especially problematic in **oncology**, where patients face **serious illness**, **treatment decisions**, and **end-of-life considerations**.

Patients and oncologists do not share the same **lived experiences, priorities, or fears**, and assuming the clinician knows what is morally best risks **undermining the patient's dignity and autonomy**.

Ethical clinical practice must therefore prioritize **respect for the patient's moral perspective and autonomy**. Physicians should engage in **compassionate dialogue**, provide **clear information**, explore **patient values**, and support decisions that reflect the patient's understanding of what matters most.

Professional ethical reasoning ensures that choices are **patient-centred, morally defensible**, and **contextually appropriate**, reinforcing the necessity of **trained, competent ethicists** rather than amateurs guided by intuition or **moral common sense**.

6.3

How to structure an ethical position?

Case Study

Tom is an 81-year-old man with metastatic prostate cancer and moderate Alzheimer's dementia. In the past, he clearly stated that he "never wanted to live in a nursing home or become a burden to others." Due to progressive cognitive decline, Tom is now unable to fully participate in complex medical decisions. His family insists on pursuing **life-prolonging therapy**, believing that he would still want to "fight" the disease.

Ethical Problem

Is the decision to pursue life-prolonging therapy ethically **praiseworthy or blameworthy**?

Solution 1 – It is blameworthy	Solution 2 – It is praiseworthy
Justification	Justification
1. Resorting to Principles (deontological approach) According to the principle of respect for autonomy, Tom's previously expressed wishes should guide medical decisions. Ignoring those wishes may violate his autonomy.	**1. Resorting to Principles (deontological approach)** According to the principle of non-maleficence and beneficence, physicians and family members may feel morally obligated to preserve life and attempt beneficial treatment when possible.
2. Resorting to Consequences (consequentialist approach) Life-prolonging therapy could extend a life condition that Tom explicitly wanted to avoid, potentially leading to suffering, reduced quality of life, and prolonged dependency.	**2. Resorting to Consequences (consequentialist approach)** Treatment could potentially prolong Tom's life, giving him additional time with his family and possibly maintaining an acceptable quality of life.
3. Resorting to Rights (liberal approach) Tom may have a right to have his prior preferences respected, particularly when they concern dignity, living conditions, and the avoidance of burdensome treatment.	**3. Resorting to Rights (liberal approach)** Family members may claim a role in decision-making when the patient lacks full decision-making capacity, especially when they believe they are acting in the patient's best interests.
4. Resorting to Traditions (communitarian approach) In some social and cultural contexts, respecting the previously expressed values of elderly individuals is seen as a way of preserving personal dignity and moral integrity.	**4. Resorting to Traditions (communitarian approach)** In many communities, there is a strong moral expectation to care for and protect vulnerable family members, which may include pursuing available treatments.

6.3

How to structure an ethical position?

When addressing ethical issues, special attention must be paid to how the problem is formulated. A well-structured ethical question focuses on evaluating a human action or decision and can be framed as:

"**Is this human action or choice blameworthy or praiseworthy?"**

This approach emphasizes the moral evaluation of conduct, rather than relying on legal rules, religious norms, or unexamined personal intuitions. Proper formulation is essential because it lays the groundwork for systematic and defensible ethical reasoning, ensuring decisions are based on moral principles rather than arbitrary judgment or intuition.

Ethical reasoning can be understood through a three-part structure:

- **The ethical problem:** identifies the moral question at stake
- **The ethical solution:** proposes a possible moral judgment or course of action
- **The ethical justification:** explains why the proposed solution is morally defensible and appropriate in the given context

Particular attention should be given to the justification of an ethical solution. Ethical arguments can be developed from different theoretical perspectives, each offering distinct insights and criteria for evaluating human conduct. Justifications may be based on

- **Principles,** associated with a deontological perspective, where moral evaluation depends on adherence to duties, rules, or ethical norms
- **Consequences,** reflecting consequentialist reasoning, which evaluates actions based on their outcomes and the benefits or harms they produce
- **Rights,** reflecting a liberal approach that prioritizes protection of individual autonomy, entitlements, and informed decision-making
- **Traditions and shared social values,** emphasized in communitarian approaches, recognizing that moral norms are shaped by the cultural and social context in which individuals live

None of these approaches is inherently superior. The most suitable framework depends on the specific ethical problem, the circumstances, and the values of the stakeholders involved. Ethical reasoning therefore requires flexibility, careful reflection, and the ability to select the most appropriate form of justification. By combining systematic analysis with sensitivity to context, clinicians and ethicists can provide morally defensible guidance, ensuring that ethical decisions are both reasoned and responsive to the complexities of real-world practice.

But take note that **without justification, there is no ethical position.**

6.4

Oncologists' ethical problems

It is the responsibility of oncologists to reflect on their actions while treating patients. These actions have ethical importance, so they can be praiseworthy or blameworthy. Oncologists should be aware of this: it is their duty.

- **Patient Information & Understanding** – Have you clearly explained test results, including false positives, false negatives, and their potential harms?
- **Early Detection Implications** – Have you discussed risks such as overdiagnosis and overtreatment?
- **Probabilistic & Statistical Competence** – Do you understand sensitivity, specificity, predictive values, and can you explain probabilistic outcomes accurately?
- **Placebo** – Are you familiar with placebo and nocebo research and its clinical relevance?
- **Breaking Bad News** – Do you communicate effectively, recognize barriers, and consider placebo/nocebo effects when talking with patients?
- **Shared Decision-Making** – Do you involve patients in treatment planning and respect their autonomy?
- **Patient Rights** – Do you inform patients of their right to accept or refuse treatment?
- **Supportive Care** – Do you integrate possible palliative and supportive care from the start of treatment?
- **Diversity & Limits** – Do you respect patients' cultural, sex, gender, and spiritual diversity? Do you know how to accommodate their requests within the clinical and cultural context in which you operate?
- **Pathology vs Person** – Do you treat not just the disease but the patient with the disease?
- **Moral Paternalism** – Are you aware of how intrusive your potential moral paternalism might be?

6.4

Oncologists' ethical problems

In oncology practice, physicians face numerous ethical responsibilities that go beyond technical treatment decisions. A central ethical question is whether **omissions in professional knowledge, communication, or clinical practice** should be considered **praiseworthy or blameworthy**. Ethical reflection becomes especially important when oncologists fail to adequately inform patients about key aspects of **medical testing, treatment, or potential outcomes**.

One major issue concerns **diagnostic information**. It is ethically problematic if an oncologist does not clearly explain the meaning of **false positive or false negative results**, or the potential **physical, psychological, existential, and social consequences** these results may have. Similarly, ethical concerns arise when clinicians fail to consider possible harms associated with **early detection**, including **overdiagnosis, overtreatment**, and the distress such interventions may cause.

A second crucial area is probabilistic **and statistical competence**. Ethical responsibility may be questioned when physicians lack sufficient understanding of **diagnostic metrics** such as **sensitivity, specificity, and positive or negative predictive values**, or when they cannot effectively interpret and communicate these indicators. Clear communication of **probabilistic outcomes** is essential, as misunderstanding or poorly explaining risk can compromise a patient's ability to make fully informed decisions.

Communication practices themselves carry ethical significance. Physicians must recognize **barriers to delivering difficult information** and understand the potential **nocebo effects** that may result from poor or insensitive communication. Familiarity with **placebo and nocebo research** is therefore relevant for ethical decision-making and patient care.

Shared decision-making is also central to ethical oncology. **Treatment plans** should be developed collaboratively, respecting **patient autonomy** and promoting empowerment. Patients should always be informed of their right to **accept or refuse treatment**, and clinicians should be aware of **palliative and supportive care options** to ensure comprehensive, compassionate care.

Oncologists must also address **patient diversity**, including **cultural, sex and gender, and spiritual differences**. Ethical reflection is needed to determine how to respond appropriately to **patient requests** while recognizing the limits of what can be accommodated contextually, ethically and medically.

Taken together, these considerations highlight the ethical importance of **professional competence, effective communication, respect for autonomy, and diversity-sensitive care**. Ethical oncology is not just about treating a disease but about **treating a person with a disease**. It requires ensuring that every **clinical decision** is **morally defensible, patient-centred, and contextually appropriate**. It also involves understanding the risks of **moral paternalism**, particularly because physicians cannot fully experience a patient's **cultural, gender, or spiritual perspective. They are not in the patients' shoes.**

6.5

Patients' Ethical/Existential Problems

Amrita is a 36-year-old woman living in London with her husband. They have been married for seven years and are the proud parents of two daughters, aged five and three.

At ten weeks pregnant with a new baby, Amrita is diagnosed with **osteosarcoma**. Her clinical oncologist presents her with two options:

- **Interrupt the pregnancy** and proceed with standard treatment, including immediate chemotherapy followed by surgery and radiation therapy.
- **Continue the pregnancy** at her own risk, adapting treatment in a way that may reduce her chances of being cured.

What should Amrita choose?

This is her ethical/existential problem: "Is the decision to interrupt the pregnancy **ethically blameworthy or praiseworthy**?"

6.5

Patients' Ethical/Existential Problems

Amrita is facing a **classic ethical/existential dilemma** that occurs **before or alongside clinical decisions**. Her situation is not purely medical; it involves deeply personal values, life priorities, and moral considerations that go beyond standard treatment protocols. She must weigh the potential benefits and harms of interrupting her pregnancy against the consequences of continuing it while undergoing cancer treatment. This decision intersects with clinical choices but is fundamentally rooted in her own ethical and existential framework.

Several questions naturally arise in such cases:

- **Should the oncologist tell Amrita what to do?**
- **If guidance is offered, on what ethical basis could it be justified?**
- **Would it be appropriate to involve a clinical ethics expert to help Amrita navigate her decision?**

These questions highlight a critical tension in oncology: the oncologist holds expertise in medicine but **cannot assume moral authority over the patient's deeply personal choices**. It is essential to recognize that:

- **Moral paternalism is wrong** – the oncologist must not impose their own values or preferences on the patient.
- **Common moral sense alone cannot guide ethical decisions** – what seems reasonable to the clinician may not reflect the patient's values, priorities, or life circumstances.
- **Oncologists are not in patients' shoes** – they cannot fully understand Amrita's perspective, including her cultural, spiritual, familial, or personal context.

In practice, the oncologist's role is to provide clear and accurate information about medical risks, probabilities, and treatment options while supporting Amrita's autonomy. This includes explaining the possible consequences of interrupting or continuing the pregnancy, the impact of treatment on both her health and the fetus, and the limits of medical knowledge in predicting outcomes. But with the help of an **ethical counsellor**, the oncologist can also gain a deeper understanding of Amrita's ethical and existential concerns.

An **ethics counsellor** can be extremely useful especially for Amrita. They can facilitate structured reflection, help her clarify her values, and ensure that her decision is both informed and morally coherent.

This case illustrates a profound challenge in oncology. Ethical decisions are often intertwined with clinical ones, but they cannot be reduced to medical judgment alone. Treating the disease is important, but respecting the person facing the disease is paramount. Ethical oncology requires sensitivity, humility, and recognition that the patient's moral and existential perspective is central to all decisions. In this sense, **ethical oncology calls for ethical counselling**.

6.6

What is the ethical/existential counselling?

Ethical counselling is a service designed to support patients and oncologists when facing ethically complex situations.

When Should It Be Implemented?

It should be offered whenever **ethical and existential choices** precede or significantly influence clinical decisions.

Why Should It Be Implemented?

Patients' and oncologists' **moral intuitions and common sense alone are not sufficient**. Specialized professionals are needed to **enhance the quality of decisions**, improve patients' quality of life, and consider the broader impact on their relatives.

What Are Its Key Features?

- **Non-directiveness** – It does not impose solutions.
- **Value neutrality** – It respects the individual's beliefs and principles.
- **Respect for autonomy** – It supports the patient's right to make their own choices.
- **Non-paternalism** – It avoids guiding decisions based on the counselor's personal values.

6.6

What is the ethical/existential counselling?

Many clinical cases highlight the **dual nature of decision-making**: medical questions about diagnosis and treatment often intersect with **ethical and existential questions** reflecting patients' values, priorities, and moral sensitivities. Not every clinical decision raises such concerns, but when it does, what should be done medically depends on what ought to be done morally, giving rise to an **ethical/existential decisional problem**.

Research shows that humans rely on an often unconscious **"moral toolkit"** shaped by personal history, culture, and social context. Emotions and intuitions reflect deeper moral principles, and some values are non-negotiable. This means that different individuals may reach different decisions when facing the same dilemma. They possess **personal moral frameworks** that act as a "conceptual and value-laden window" guiding their choices and actions.

Oncologists should recognize that they **cannot impose their own choices**. Moral paternalism is wrong, and intuition or common sense alone is insufficient when patients face profound ethical/existential dilemmas. Decisions require careful facilitation, with the support of an **ethics counsellor:** an expert who helps patients both reflect on their personal moral frameworks and make choices that are morally coherent and aligned with their life priorities.

In **personalised oncology**, treatment is tailored to the patient's biological characteristics, and **ethical counselling** complements this approach by ensuring decisions align with the patient's moral and existential framework, making care both technically appropriate and personally meaningful.

Ethical counseling supports both patients and clinicians in navigating ethical and existential problems. It provides a **reflective space** to examine intuitive responses, clarify values, and identify non-negotiable principles, without imposing solutions. Ethical counseling complements personalized oncology by ensuring treatment decisions are **clinically sound and ethically attuned**, respecting the patient as a whole person rather than as a disease to be treated.

Summing up, an ethical counselor helps:

- **Patients (or relatives)** clarify, in a non-directive and non-paternalistic way, their ethical/existential problems and potential solutions when these precede or intersect oncological decisions.
- **Oncologists** gain a complete understanding of the ethical/existential context, allowing them to interact with patients and relatives in a **morally aware, non-directive, non-paternalistic, and autonomy-respecting way**.

6.7

Ethics in Clinical Oncology – Take Home Messages

What Ethics Is

- Systematic evaluation of human actions as praiseworthy or blameworthy
- Guides decisions about what people ought to do
- Provides rational tools for moral reflection beyond intuition or habit

Ethics vs Other Normative Systems

- Ethical reasoning must be distinct from Law (rules and legal obligations) Religion (theological authority) Personal moral prejudices These may influence ethics but cannot replace ethical analysis

Common Errors in Clinical Ethics

- Reliance on "moral common sense" or intuition
- Moral paternalism (imposing clinician values on patients)
- Lack of professional ethical competence

Structure of Ethical Reasoning

- Ethical problem
- Ethical solution
- Ethical justification

Types of Ethical Justification

- Principles and duties (deontological)
- Consequences and outcomes (consequentialist)
- Individual rights and autonomy (liberal)
- Social traditions and shared values (communitarian)

Oncologists' Ethical Responsibilities

- Professional competence and statistical understanding
- Clear communication of risks and uncertainties
- Respect for patient autonomy
- Shared decision making
- Sensitivity to cultural, gender, and spiritual diversity

Role of Ethical Counselling

- Helps patients clarify values and moral priorities
- Supports non paternalistic decision making
- Helps clinicians understand ethical and existential contexts

Key Principle

- Ethical oncology treats **the person with the disease**, not only the disease.

6.7

Ethics in Clinical Oncology – Take Home Messages

Ethics is the systematic evaluation of human actions or omissions to determine whether they are morally praiseworthy or blameworthy. It provides a framework for critically assessing what people do and what they ought to do, guiding responsible decision making beyond instinct, habit, or social convention. In clinical contexts, ethical reasoning must remain distinct from other normative systems such as law, religion, or personal moral prejudices. Although these systems may influence ethical reflection, they cannot replace ethical analysis because they rely on different sources of authority and justification.

In clinical ethics, particularly in oncology, a common mistake is relying on "moral common sense" or intuition rather than structured ethical reasoning. Personal intuitions are often shaped by cultural assumptions or biases and may lead to inconsistent or harmful judgments. Another major risk is moral paternalism, where clinicians impose their own values on patients instead of respecting the patient's moral perspective and autonomy. Ethical medical practice requires professionals trained in ethical principles who can engage patients through informed dialogue, transparency, and shared decision making.

Ethical reasoning follows a structured process that includes identifying the ethical problem, proposing a solution, and providing a justification. Justifications may draw on different theoretical perspectives none of which is inherently superior; the appropriate framework depends on the specific context and stakeholders involved. **Without justification, no ethical position can be considered valid.**

In oncology, ethical responsibility extends to professional competence, clear communication, and respect for patient autonomy. Physicians must ensure that patients understand diagnostic uncertainties, probabilistic information, treatment risks, and potential harms such as overdiagnosis or overtreatment. Ethical practice also requires awareness of communication effects, including placebo and nocebo influences, and sensitivity to cultural, sex and gender, and spiritual diversity.

Ethical counseling can help patients clarify their values and make morally coherent decisions, while also helping clinicians understand the ethical context of care.

Ultimately, ethical oncology is patient centred: it combines clinical expertise with structured ethical reasoning to respect patient autonomy, values, and dignity, treating not only the disease but the person living with it. Moreover, it needs an ethical counselling service

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