ETHICS

Improving Cancer Care through Health Information Technology: Ethics and Practicality

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The Ethics of Health Information Technology in Oncology: Emerging Issues from Both Local and Global Perspectives

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OVERVIEW

Health information technology (HIT) is ever-increasing in complexity and has incrementally become a fundamental part of our everyday clinical lives. As HIT becomes more complex and commonplace, so do the questions it raises about stewardship and usage of data, along with the ethics of these applications. With the development of rapid-learning systems, such as ASCO’s CancerLinQ, careful thought about the ethics and applications of these technologies is necessary. This article uses the principles-based framework of modern bioethics to examine evolving ethical issues that arise in the context of HIT and also discusses HIT’s application in reducing cancer care disparities in the developing world. We recognize that this topic is quite broad, so here we provide an overview of the issues, rather than any definitive conclusions about a particular “correct path.” Our hope is to stimulate discussion about this important topic, which will increasingly need to be addressed in the oncology community.

Health information technology (HIT) is ever-increasing in complexity and has incrementally become a fundamental part of our everyday clinical lives. The clinical world is constantly changing: electronic health records (EHRs) are nearly ubiquitous, the use of mobile health technologies is on the rise, and the electronic collection of patient-reported outcomes data (ePROs) is increasingly common outside the research arena. As HIT becomes more complex and commonplace, so do the questions it raises about stewardship and usage of data, along with the ethics of these applications.

The dissemination of EHRs into widespread clinical practice, for example, allows for greater sharing of patient data across health care systems, as well as between patients, health care providers, payers, professional societies, regulators, and commercial entities specializing in data aggregation and analysis. Federal and state laws do impose some protective, legal requirements in this area, but a truly ethical health care system must have the ability to identify and promote ethical behavior independent of statutory action and to self-regulate its use of HIT.

ASCO’s CancerLinQ is one example of a strategic effort to maximize the utility of the growing HIT infrastructure, to harness the power of data into a “rapid learning system,” an engine of constant quality monitoring and improvement. In this way, HIT is increasingly seen as a matter of quality improvement and is often implemented as a purported best practice standard. However, this is sometimes done without adequate attention to the ethical issues raised by its deployment. This article will thus call on the principles-based framework of modern bioethics to examine evolving ethical issues that arise in the context of HIT and discuss its application in reducing cancer care disparities in the developing world.

We recognize that this topic is quite broad; we cannot cover it completely here, nor do we assert to. Rather, this chapter is intended as an introduction to the issues, to serve as a catalyst to spur further discussion of related dilemmas as they evolve with our technology. Here we provide an overview of the issues, rather than any definitive conclusions about a particular “correct path” for HIT. We will raise questions rather than provide conclusive answers.

A DEFINITION

It is important to begin with a clear statement about what counts as HIT. In some ways, HIT is a catchall term describing a broad spectrum of technological applications to health care. These might include things like electronic medical records, mobile health solutions—such as software to collect ePROs directly from patients—other mobile phone-based platforms, data repositories, and databases, or even telemedicine technologies. A working definition must also, however, account for the crosstalk and complex interaction of these technologies within our health care system. We will...
thus employ the Institute of Medicine (IOM) definition, which accounts for the rather divergent nature of these products and the complexities of their interaction:

“Health IT is not a single product: it encompasses a technical system of computers and software that operates in the context of a larger sociotechnical system—a collection of hardware and software working in concert within an organization that includes people, processes, and technology.”

BACKGROUND

HIT is value-neutral; this technology is neither “good” nor “bad,” inherently. Rather, its value stems from the manner in which it is applied. It is obvious that proper application of HIT stands to improve the quality and safety of care. It is also just as likely, however, that misapplication may introduce risks and potential harm to patients, as the IOM points out in its report, “Health IT and Patient Safety.” As HIT grows in complexity and frequency of application to our clinical practice, this possibility warrants careful consideration.

Historically, discussions of HIT ethics have focused on privacy concerns. Mostly these amount to questions about security, such as (1) where the data “sits,” (2) who has access, (3) what kind of information is contained therein, and (4) what might happen if it were leaked. Ethical principles clearly mandate that reasonable efforts be made to safeguard a system from unauthorized access, that usage is scrutinized and monitored, and that overall privacy is maintained. But these concerns only scratch the surface of issues raised by HIT.

To complicate matters, however, it is also possible that the pursuit of any one of these goals may at times be in conflict with another or with another ethical imperative. This stresses the importance of IOM’s fifth stated goal, which seeks to balance any potential improvements to society with the privacy rights of individuals. In other words, a highly desirable outcome, such as improving population health, does not necessarily justify or legitimize the injudicious use of protected health information (PHI). Appropriate protections are needed within all HIT systems, regardless of how data are used.

Higher-level usages of data, however, may require further ethical consideration. Rapid-learning systems, for example, seek to harness the power of large datasets to gain new insights. These may have a low potential for harm, whereas the payoff in health improvement may be quite significant. Should these usages be treated like other routine ones in HIT, such as those arising in the context of clinical care or quality improvement initiatives? Are they more like public health studies, which allow aggregation of patient data without obtaining prior consent? Or are they more like research, since they must maintain linkages to particular patients and outcomes to be maximally useful? We must grapple with these questions as HIT and learning health care systems evolve. Although these forms of secondary data use may improve population health through comparative effectiveness research, they may also incur added privacy risks. What safeguards are necessary within rapid-learning systems and other forms of HIT? We must carefully consider this question within the oncology community and the society at large.

KEY POINTS

- Health IT (HIT) is value-neutral; this technology is neither “good” nor “bad,” inherently, but rather its value stems from the manner in which it is applied.
- The evolution of rapid-learning systems, such as ASCO’s CancerLinQ, increasingly blurs the line between research and high-quality clinical care.
- The most salient area of potential harm imposed by HIT is the loss of privacy, but complete de-identification of data would negate the enormous promise of learning health care systems. We must find the right balance between individual privacy rights and potential societal benefits in applying rapid-learning systems in oncology.
- In addition to the traditional principles of biomedical ethics, discussions about the ethics of HIT must also include considerations of data liquidity and fidelity and notions of the health care system as “curator” of potentially valuable data.
- The application of HIT in the developing world stands to improve access to and quality of cancer care.

beneficence, nonmaleficence, autonomy, and justice. We also describe two nontraditional constructs that are useful in considering ethical issues in HIT: fidelity and the role of the health care system as “curator” of data.

A PRINCIPLES-BASED LOOK AT THE ISSUES

Beneficence

The IOM has defined five overarching goals for a digital health care system:

1. Improve quality, safety, and efficiency, and reduce health care disparities.
2. Engage patient and families.
3. Improve care coordination.
4. Improve population health.
5. Ensure adequate privacy and security protections for personal health information.

These overarching goals provide a litmus test of ethical behavior by which to evaluate the use of HIT. The first four goals relate to the principle of beneficence—which mandates that we “do good”—as each seeks to achieve an improved state of being, whether for an individual patient or the larger public. Although there are certainly other potential uses of HIT that could bring sizeable benefit to patients, the use of HIT data along the lines of the IOM’s stated goals clearly meets the criterion of beneficence.

To complicate matters, however, it is also possible that the pursuit of any one of these goals may at times be in conflict with another or with another ethical imperative. This stresses the importance of IOM’s fifth stated goal, which seeks to balance any potential improvements to society with the privacy rights of individuals. In other words, a highly desirable outcome, such as improving population health, does not necessarily justify or legitimize the injudicious use of protected health information (PHI). Appropriate protections are needed within all HIT systems, regardless of how data are used.

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Nonmaleficence (Avoidance of Harm)
The most salient area of potential harm imposed by HIT is the loss of privacy, or compromised security of PHI, as addressed in the fifth IOM goal. Privacy is not only an ethical imperative for HIT, but it is also a legal requirement under the Health Information Portability and Accountability Act (HIPAA). In particular, the HIPAA “Privacy Rule” lists 18 data element types that must be removed from patient data for the patient to be considered de-identified for uses outside of treatment, payment, and health care operations. De-identification of health data presumptively precludes identification of individual patients, thereby preserving privacy. However, irreversible de-identification would severely constrain the usefulness of such data for advancing the public good through data aggregation and analysis. Indeed, linking longitudinal health data—especially those that describe health outcomes—is necessary for programs such as ASCO’s CancerLinQ; this is precisely the mechanism through which it seeks to generate new knowledge about cancer care. Re-identification of data to allow this can be accomplished through a variety of complex de-identification processes, but each involves a third party to perform the de-identification, which itself poses a risk of privacy compromise.

We know of no automated ways to completely strip an EHR of all identifiers. In particular, free text notes are known to contain randomly distributed identifying information that can be difficult if not impossible to remove. For example, a note might describe the patient as the mother of the state governor. In one published example, authors were able to re-identify patients through analysis of an article’s figures, which included maps of patients’ domiciles, even at the limited figure resolution of the published journal. A more troubling question is whether genomic data can ever be de-identified, given the potential to identify patients through their genome, and subsequently used as a link to family members. The Icelandic Supreme Court has ruled that a family member has the right to prohibit the third party use of another family member’s genetic information because of the potential to identify that family member and thereby cause harm to that individual. How can we maximize utility of patient data to society while also protecting individual patients and their PHI?

Autonomy
The principle of autonomy emphasizes the importance of patient preferences and beliefs in these debates, in recognition of the right to self-determination. HIT can have both positive and negative effects on patient autonomy, depending on one’s perspective and the manner in which it is deployed or employed. It can increase patient autonomy, for example, by providing improved access to personal health data and enabling more meaningful engagement of patients and families with the health care system. At the same time, it has been argued that HIPAA’s Privacy Rule, by allowing secondary use of de-identified data without consent, may diminish patient autonomy. Rothstein, for example, argues that the knowledge generated through data aggregation might relate to areas of societal conflict, such as abortion, in which case some patients would have objected to contributing their data had they been aware of this usage.

This is perhaps the central dilemma posed by data usage in rapid-learning systems and HIT in general: how should we, as a society, and within our systems, balance data use between potential benefits to society and potential harms to individuals?

Justice
The principle of justice is often conceived as “fairness.” In this way, it may be said to warrant equal distribution of the risks and benefits of an intervention. The benefits of HIT, however, are in some ways dependent on access to this relatively expensive technology. Equal access is thus not always possible; poorly funded health care systems and indigent or technically unsophisticated patient populations are placed in a disadvantageous position. In recognition of the significance of this distributive justice problem, we will introduce and discuss some global ethical implications of HIT separately.

The principle of justice also requires that patients be notified of any real or potential breaches involving their PHI. Security breaches have and will continue to occur, despite measures taken to secure sensitive information. Ethical behavior requires prompt patient notification when a breach has occurred and that mitigation steps are taken. The American Medical Association’s Code of Medical Ethics was revised in 2009 to clearly state this obligation. Furthermore, the Health Information Technology for Economic and Clinical Health Act of 2009, part of the American Recovery and Reinvestment Act, mandates patient notification by the health care provider when breaches occur.

Nontraditional Concepts
Fidelity
Electronic medical records are becoming notorious for indiscriminate use of editing features such as cut and paste. Errors in the medical record often become propagated indefinitely. Furthermore, corruption of data fidelity or misinterpretation of data outside its original context compromises the trustworthiness of any generalizable knowledge derived from its use. As is often said colloquially, “Garbage in equals garbage out.”

The four traditional principles of modern medical ethics would seem to mandate significant efforts to ensure data integrity and utility, especially through the principle of nonmaleficence given the potential harm that may result from errors in medical documentation or misuse of data. This duty to ensure data fidelity is additional to, and separate from, the importance of security safeguards, as discussed above. HIT innovations and safeguards must recognize the difference between these two important issues. A higher-level but important aspect of fidelity is the notion of “data liquidity,” whereby data systems and structures facilitate more seamless integration and interaction with other systems; this is an essential component of an efficient, functional learning health
care system. The principle of justice mandates that we maximize the ability of these systems to yield improvements for society, provided that individuals and their data are adequately protected.

Ownership of Data and the Health Care System as “Curator”

The aforementioned four principles of modern bioethics—beneficence, nonmaleficence, autonomy, and justice—derive from a philosophy and value system established in the aftermath of World War II, in response to the recognition of many patient abuses, often conducted in the name of research. Indeed, most of these regulatory controls pertain to clinical research. As stated in HIPAA’s Privacy Rule, treatment and health care operations are exempt from this regulation, in accordance with the traditional view that routine clinical care is distinct from research. However, the ability to search, aggregate, and manipulate large amounts of data through HIT is increasingly blurring these margins. Are rapid-learning systems tools of research or systems of high-quality clinical care? In many important ways, they are arguably both.

In a paper world, the opaqueness of the medical charting system afforded significant protections. In an electronic world, the forest need not be lost for the tree; both are readily discoverable. The blurring of the lines separating research from routine clinical care has raised the question of which ethical behavioral constraints, now standard in the research environment, should apply to generalizable knowledge derived from data that are collected in the course of routine patient care.12,13

Clearly the recording, retention, and maintenance of readily accessible data come at a very high cost, a cost that is carried by the health care system. Does this therefore constitute data ownership? Or does the patient “own” the data? Both have reasonable claims to it. The patient has certain rights, such as privacy, security, fidelity, and timely access to personal information and health records. However, this remains distinct from any claims to intellectual property rights regarding generalizable knowledge arising from the aggregated use of that data. Those insights, or even intellectual property rights, may have high scientific, social, or commercial value. The ethics of such scenarios remain murky.

Health care systems and providers have assumed new ethical obligations resulting from their role as “curators” of data. Some of these obligations are delineated in the American Medical Informatics Association Code of Professional Ethical Conduct, but significant ambiguity remains.14 The vast majority of patient data will continue to reside in the electronic medical record. With the large capital and operation expense of supporting HIT and the increased capabilities of “big data” mining combined with machine learning, it is inevitable that the secondary use of data will be pursued for both the greater good of population and public health and the revenue stream that can support HIT. Both traditional and transformative views of ethical behavior must apply; we must decide as a community how we will achieve the often-conflicting goals of protecting individual patients while maximizing our contribution to society through optimal data use.

HIT and Cancer Care in the Developing World

The central ethical issue in cancer care in the developing world is one of scarcity. Although many of our treatments can cure, or substantially extend life, these therapies are not available in much of the developing world. What should we say to a child in a sub-Saharan African nation with Burkitt’s lymphoma, for whom we know of inexpensive, highly curative chemotherapy but no way to provide it there? Should it be considered a basic human right to have access to curative therapies for cancer? There are numerous barriers to bringing cancer care to many developing countries, and overcoming these obstacles will take work on many fronts. HIT and technology in general are playing an increasingly important role in bridging this care gap through three important mechanisms: (1) facilitating the tracking of local disease patterns with cancer registries, (2) EHRs, and (3) tele-medicine and clinical decision support.

Cancer Registries

One can find published estimates about the incidence of cancer in any country in the world, but many of these estimates are likely quite inaccurate. This is true for many reasons, but first and foremost this inaccuracy results from the absence of a tumor registry. As such, one powerful intervention to bring cancer care to these settings is to have patients stand up and be counted. Understanding geographic cancer incidence and outcomes is critical for developing strategies to improve care. Unfortunately, these patients are not being “counted” in any meaningful way for a few key reasons.

First, many developing nations have no pathology capacity. As such, no biopsies are performed and no pathology records exist. Cancer registries are traditionally derived from pathology reports, which provide reasonable confirmation of diagnosis. This is the method used in the United States and other developed countries, where cancer is a reportable disease to state and national registries using pathology reports as the initiating event.

A lack of IT infrastructure also precludes the organization and collection of health data in most parts of the developing world. Fortunately, this is changing. Several international organizations are anxious to assist countries in developing cancer registries. For example, the International Agency for Research on Cancer has launched a Global Initiative for Cancer Registry Development in Low- and Middle-Income Countries.15 Aimed at low- and middle-income nations, this program is a great asset. Still, many countries have had difficulty prioritizing this work against the countless other demands made on governments and ministries of health. In resource-poor settings, the creation of an IT infrastructure and the dedication of personnel for this activity are not trivial undertakings.
Aside from the problem it poses for cancer registries, the absence of pathologic confirmation yields other major problems for cancer care in the developing world. Consider the example of a 13-year-old boy with a mediastinal mass. Without a pathologic diagnosis, one cannot know how to accurately “count” this patient in a registry, but more importantly, one also cannot know how to treat him properly. He might have Hodgkin lymphoma, large cell lymphoma, or even acute lymphoblastic leukemia. Thus, even if a registry system exists, it is of dubious utility without decent pathologic information. Similarly, other key information such as disease stage is often missing. Stage at presentation is critical for patients in the developing world.

In developed countries such as the United States, national cancer registries serve many purposes. Treatment specifics and survival are tallied therein, giving us a picture of our progress in cancer care and highlighting areas for improvement. Attaining this follow-up data is not a trivial matter, as it requires considerable effort and expense. It may be even more costly and difficult in developing countries, where patient follow-up is patchy and patients are more difficult to track down.

**EHRs**
EHRs do not exist in most developing countries, but their deployment therein would be enormously helpful. For example, EHRs would make it infinitely easier to track patients, to know when they were due for follow-up or their next treatment, and to track outcomes. Although open-source EHRs exist, they still require an IT infrastructure and customization for a patient population, including language appropriateness and patient identification standards suitable for the environment, along with personnel training on the use.

These barriers loom large in the developing world. In many locations, patient volume is out of proportion to staffing, particularly for physicians and nurses. Just getting through the day and handling the countless emergencies makes prohibits additional activity such as EHR utilization. Physicians and nurses are often unfamiliar with EHRs and other computerized technology and struggle just to adequately document care using existing paper methods. Furthermore, open-source EHRs often lack oncology-specific functionality to facilitate tracking of tumor staging or chemotherapy administration, limiting their utility in cancer care. Building these functionalities requires expertise, time, and funds, each of which is significantly limited in the developing world.

**Tele-Medicine**
In many low- and middle-income countries, key medical personnel are either in short supply or wholly unavailable. This problem is unlikely to improve much for years to come. As such, to bring safe, effective treatment to patients in these settings, virtual partnerships with remote medical centers will be necessary. Such partnerships are effective and feasible. The following are important cast members and components of care.

**Medical oncology.** An increasing number of countries deliver cancer care without many, or any, oncologists at the care site. This is accomplished through partnering with an academic cancer center in another country. An EHR facilitates this work, allowing remote cancer center personnel to access systems of care to review records in preparation for virtual conferences and tumor board sessions.

**Pathology.** Pathology capacity has two essential components: processing and professional interpretation. Although both components are absent in most developing countries, the latter can be provided virtually, using tele-health technology including videoconferencing and remote EHR access. Numerous platforms exist to facilitate remote video pathology. The best of these systems do not require large bandwidth for live image transfer and have the ability to create databases that can be tapped for clinical care and research. This leaves only the barrier of physical specimen processing, including tissue fixation, paraffin embedding, slicing, and staining. Though significant, this barrier can be addressed more readily, since it would not require the local presence of a highly trained pathologist.

**Radiology.** Imaging is essential in the management of most cancers, from staging and assessment of treatment response to recurrence monitoring and diagnosis of complications. Plain X-rays are commonly available in the developing world, as are ultrasound machines. CT and MRI scanners are less reliably available, and PET technology is typically absent because of the need for a cyclotron in close proximity to provide the required radioisotope. Much like the pathology conundrum, however, radiology has two central components: image acquisition and interpretation. Tele-health solutions allow for the latter to be done remotely, provided that sufficient IT infrastructure is present to maintain and transmit images. This leaves only the barrier of radiologic equipment and the need for technicians to perform scans. Although not insignificant, this too is achievable in parts of the developing world, especially with financial support and technical knowledge from partnering medical centers.

**Clinical decision support through smartphones.** Smartphones, operating as handheld computers, have the ability to provide clinical decision support (CDS) for health care providers. CDS can be customized for any number of practice settings, since diagnostic and treatment options will vary widely depending on the locale. They can also be rapidly updated as new testing or treatment becomes available or as we learn more about delivery of therapy in a specific setting. This technology holds promise for improving cancer care in the developing world, as it decreases the handicap posed by the
CONCLUSION

This article has provided a general overview of ethical issues posed by the proliferation of HIT in modern cancer care and reviewed the role of HIT in reducing cancer care disparities in the developing world, which itself has significant ethical implications and importance. We hope this work will generate meaningful discussion about issues that continue to evolve in their importance and complexity, particularly regarding rapid-learning systems such as ASCO’s CancerLinQ.

Using the framework of modern bioethics, this article highlighted the central tension and dilemma herein: the competing demands of individual patient protection and benefits to society. In situations where the line between research and clinical care are increasingly blurred, this classic bioethical dilemma takes on new life and significance and warrants much thought and consideration in the oncology community. In our growing role as “curator” of data, how do we balance the security and privacy rights of individuals with the societal benefits of more open-access data use, in light of potential lessons to be learned about improving comprehensive cancer care? And how do we utilize developing HIT to promote justice and equity in access to cancer care in the developing world, where resource limitations hamper the provision of even basic and curative treatments? We do not pretend to have the answers to these dilemmas, but we hope that in outlining and posing them here, we will contribute to and stimulate the dialogue about these essential issues. This is only the beginning of the conversation; the list of issues, concerns, and opportunities is much longer than as posed here and will continue to grow. A central task over the next decade is to openly address these issues and as yet unforeseen ones, as HIT becomes progressively more ubiquitous in cancer care and cancer research.

Disclosures of Potential Conflicts of Interest

Relationships are considered self-held and compensated unless otherwise noted. Relationships marked “L” indicate leadership positions. Relationships marked “I” are those held by an immediate family member; those marked “B” are held by the author and an immediate family member. Relationships marked “U” are uncompensated.


References


ETHICS

Supportive, Palliative, and End-of-Life Care: Similarities, Differences, and Integration

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Early Integration of Palliative and Supportive Care in the Cancer Continuum: Challenges and Opportunities

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OVERVIEW

Palliative care has become synonymously associated with hospice care in the minds of patients and physicians. Supportive care is a more acceptable term and leads to earlier referral. Miscommunication and a “collusion of hope” centered on cancer treatment is detrimental to care at the end of life and results in complicated bereavement. Patients, despite being told prognosis, may not comprehend the news even if delivered in an empathetic manner. There are resource and policy barriers to palliative care. However, integration of palliative care early in the management of advanced cancer has demonstrated multiple benefits without reducing survival.

Supportive care, palliative care, and end-of-life (EOL) care are used to describe clinical programs with the primary aim of assessing and managing physical and psychosocial distress in patients with cancer and their families. Common to these programs are multidisciplinary assessment and management of common physical symptoms, and psychosocial distress with attention to the environment where patients and families receive care.

EOL care originated in the United Kingdom during the 1960s with the establishment of the hospice movement.1 Patients with advanced cancer off “active therapy” were treated by interdisciplinary teams in inpatient hospices and later in the community. The term hospice in the United States reflects services delivered under the Medicare hospice benefit.2 Initially, American hospices were not-for-profit, but in recent years the majority of patients are treated by for-profit hospices; 80% are treated at home by nurses with limited physician visits. The average duration of hospice care is 3 weeks before death; the majority have discontinued cancer treatment.

The term palliative care was coined by Dr. Balfour Mount, the founder of the first North American acute palliative care unit at the Royal Victoria Hospital in Montreal, Quebec, Canada. Benefits of this unit in an acute care facility were published in 1976.3 Since then, palliative medicine has evolved into a medical subspecialty in the United States, Europe, Australia, and in many developing countries. Palliative care programs modified EOL care that emerged during the hospice movement, adapting it to patients admitted to acute care facilities and for outpatients with earlier stages of cancer.4,6 Early access to palliative care not only improves physical and psychosocial symptoms, but may improve survival over aggressive cancer treatment at the EOL.7

A recent survey among comprehensive and noncomprehensive cancer centers in the United States found the majority had inpatient palliative care consult teams; only a minority had acute palliative care units.8 This is concerning since these units are effective in reducing physical and emotional distress.9,10 It is also concerning that most cancer centers do not have outpatient palliative care services. Outpatient consults are the only way to provide early palliative care for patients with cancer. Unless outpatient services are established, most patients with cancer will suffer unnecessary distress and potentially decreased survival.

The term supportive care emerged from the oncology to include measures to support patients undergoing cancer treatment.11,12 Supportive care teams are skilled in managing chemotherapy-induced emesis, cytopenias, infections, mucositis, and cancer-related symptoms. The Multinational Association of Supportive Care in Cancer (MASCC) has developed a body of knowledge, a successful meeting, and journal related to supportive and palliative care.

Concepts and definitions for supportive care, palliative care, and hospice care were the focus of a recent systematic review.13 Common concepts are symptom control and quality of life for patients with life-limiting illness. Supportive care focuses on reducing toxicity to cancer treatment and less often involves interdisciplinary care. Hospice care focuses on bereavement, community care, and volunteer support. Both palliative care and supportive care are applicable to early cancer care. Hospice and palliative care are delivered by palliative medicine specialists. Two national professional organizations use both terms in their name, the National Hospice
and Palliative Care Organization (NHPCO) and the American Academy of Hospice and Palliative Medicine (AAHPM). Both have annual meetings.

Since both terms are used together, not only medical oncologists but also patients and families perceive palliative care as closely associated with hospice and EOL care. A survey among a random sample of medical oncologists and midlevel providers showed that the majority were less likely to refer a patient with early-stage cancer to palliative care as compared to a service named supportive care; 44% of providers perceived the name palliative care as a barrier to referral, related to the perception that palliative care decreases hope among patients and families.12

As a result, our team changed the name of the outpatient palliative care center to Supportive Care Center. This change resulted in a 41% increase in patient referrals mostly to the outpatient clinic and a change in the time of referral from 4.7 to 6.2 months before death. 15% of the patients referred after the name changed did not have advanced cancer compared with 4% before the name changed.13

Figure 1 shows a conceptual model of the delivery of supportive, palliative, and EOL care. The most effective approach for patients, families, and the referring medical oncologist is that all these services be delivered by a single integrated team capable of providing multidimensional, interdisciplinary patient and family assessment and management throughout the trajectory of cancer.

**IMPEDEMENTS TO PALLIATIVE CARE INTEGRATION INTO ONCOLOGY**

In a study of newly diagnosed patients with metastatic colon and lung cancer undergoing chemotherapy, the majority felt there was the potential for cure.13 This misunderstanding was greatest among patients who rated their oncologist a “good communicator.” Patients enter palliative chemotherapy for survival rather than symptom benefit as the main motivator.14,15 Survival is not infrequently misconstrued as cure. Nearly half will undergo chemotherapy for 1% benefit, 40% if no significant benefit can be reasonably expected. There is a gap between what is expected of palliative chemotherapy and what can be reasonably expected. One reason for offering chemotherapy regardless of benefit is to maintain hope (albeit falsely), which delays discussions about EOL care.4,16 “Active treatment” provides a sense of doing something rather than doing nothing. Discussing EOL care and dying while being offered palliative chemotherapy is confusing to patients.17 “Watchful waiting” asymptomatic metastatic incurable cancer and “best supportive care” are often misconstrued to mean the “oncologist is not an expert,” “he or she does not know what he or she is doing,” or the patient assumes their outlook is worse than verbalized by the oncologist.18 Palliative chemotherapy and target-specific agents in asymptomatic patients may be presented as therapy to “prevent” future symptoms or delay progression of cancer as the “only choice.”19

Quality of life is often given as the purpose underlying palliative chemotherapy, but drug approval is largely based on survival or progression free survival benefits. Symptom control and quality of life have traditionally been secondary outcomes. Few oncologists routinely use validated quality-of-life questionnaires in practice to gauge the merits of palliative chemotherapy but uniformly use “tumor burden” and tumor measurements as a means of determining benefits to palliative cancer therapies (which correlate poorly with symptoms, survival, and quality of life).

Physician-assessed symptoms correspond poorly to patient-reported experiences.20 A subset of patients who undergo palliative chemotherapy experience severe adverse reactions requiring hospitalization. Once recovered, the same patient is offered the same approach (despite demonstrated intolerance to palliative chemotherapy) with the goal of “controlling the cancer.” Patients who are passive in decision making regarding choices of palliative chemotherapy during consultation actually have a high preference for chemotherapy because they know it would be offered by their oncologist.21 Physicians remain the major source of medical information, and the means through which this information is framed influences patient choices.

Most attention in consultation is spent on the best approach to active treatment, whereas alternatives such as

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**KEY POINTS**

- Supportive care as opposed to palliative care generates earlier referrals and greater shared care.
- A “collusion of hope” in cancer treatment delays appropriate end-of-life care and complicates bereavement.
- Communicating prognosis and comprehending survival frequently does not occur simultaneously.
- Early collaboration between an oncologist and a palliative care specialist for those with advanced cancer improves symptoms and reduces aggressive cancer care at the end of life without shortening survival.
palliative care and watchful waiting are addressed in a single sentence, if at all. Very little time is spent on the patient’s declining health, the adverse influence of cancer and treatment on work, sexuality, social relationships, and emotions and lost opportunities. A collusion of hope develops between physician and patient by whom active treatment is the answer to disease, hopes, and fears. Survival become increasingly important in the mind of patients with subsequent salvage chemotherapy; in reality, most studies suggest little survival benefit to chemotherapy following the initial two to three regimens. Mortality salience is placated by salvage therapy. Although being taken off treatment is perceived to portend a shortened survival, and a passive approach to disease management, evidence suggests the opposite, with improved survival. The end result is impaired communication, inappropriately aggressive cancer care characterized by chemotherapy within 2 weeks of death, delayed hospice referral, increased intensive care admissions, hospitalizations, complicated grief for families, and increased health care expenditures.

WHAT PATIENTS HEAR WHEN GIVEN BAD NEWS
It is easy to blame physicians for patient misunderstandings of palliative chemotherapy. Physicians occasionally use countering, buffering, or blocking techniques to spare patients the full implication of incurable cancer. On the other hand, bad news—even delivered in an empathetic and pristine manner—may not be comprehended. Such news can be met with shock, dissatisfaction, or anger. Functional denial is used as an appropriate coping mechanism when comprehension is delayed.

For some, a cascade of understanding unfolds over the disease course. What was told becomes reality and is finally comprehended. There can be a stunning, shocking, or numbing effect when one begins to grasp the worst. Acceptance is incremental and takes time for most. Responses are somatic, visceral, even expressed as frustration over the inability to comprehend. Patients develop conflicting thoughts, or their “head is full of air” as they grapple and are dazed by the news, or express “feelings of being unreal.” Metaphors expressed by patients include “news beginning to sink in,” “poring over the news,” “digesting the news,” or “feeling the weight.” Individuals who begin to suspect their poor prognosis but are not comfortable in asking may trick physicians into giving cues by asking about future plans. Patients will take “distancing” words and body language by physicians as bad news if not told directly about outlook.

BARRIERS

Resources Barriers
One percent of NIH funding is devoted to palliative care. In a MASCC international survey on integration of palliative care into oncology, more than 80% of cancer centers considered integration of palliative care into oncology as important, but only a minority of institutions (17%) was likely to expend resources toward integration. The average number of full-time physicians per program was two; most programs are under-resourced and overworked. Palliative medicine fellowship programs are rarely supported by Medicare graduate medical education funding; most fellowships depend on philanthropy or funding from other sources.

Exposure of Oncologists to Palliative Care
Most referrals to specialist palliative care services (SPC) occur within 30 to 60 days of death. Reasons include physician practice styles, lack of knowledge about palliative care, lack of standardized criteria for referral, and inequitable access to services. In a survey involving European oncologists, 88% felt they should guide EOL care. However, only 42% felt adequately trained to do so. Referral is most often based on prognosis rather than symptoms.

On the other hand, unwillingness of SPC to follow patients on chemotherapy is also a significant barrier. Often hospice and palliative care services are presented to patients as what cannot be done. Patients are taken off treatment when SPC services are consulted in a transitional model, which implies palliative care is somehow “less care.”

Oncology trainees who have rotations on SPC are more likely to refer in practice. Unfortunately, the majority of oncology trainees in current training programs have limited experience with SPC. In practice, they are at risk for burnout and “learned helplessness.” Pain management is learned by trial and error.

Public Exposure
Public exposure to developments in oncology is usually based on sensational “N of 1” experiences. Such experiences are rarely negative or within the context of realistic expectations. Toxicity is presented in general terms rather than in-depth. Public expectations of breakthroughs delays appropriate palliative care referrals and EOL care.

Health Care Policy
There is inconsistent evidence on which to establish palliative care policy. Research to establish an evidence base for SPC requires complex interventional trials and adaptability to what works and does not work with well-defined patient outcomes. Globally recognized palliative objective and subjective outcomes need to be established. Different randomization strategies, such as “step wedge” and “fast track,” are needed in these trials. Few palliative care specialists are trained researchers and able to carry out these studies successfully. Another impediment is the lack of uniform palliative care quality indicators. In a systematic review, clinical quality indicators were overly represented whereas organizational indicators were underrepresented. Most quality indicators were developed for one country, region, or care setting. Consensus around palliative quality indicators is in its infancy.

Policy is often governed by cost-effectiveness. If policy regarding inpatient palliative care is based on economics alone, the findings would be unfavorable for inpatient units. On
palliative units, patients are more likely to receive opioids appropriately but cost is higher compared with patients treated on other inpatient units. The death rate is higher (odds ratio [OR] 11.0). As a result, without comparing patient mix, policymakers are likely to determine that palliative inpatient units are lost causes. However, patients on palliative units have greater symptom severity, increased psychosocial problems (OR 2.0), greater physical suffering, and higher complexity of care. This is explained by late referral of patients suffering from more complex symptoms. From a health care policy point of view, the potential of palliative care can only be achieved when provided by a team of SPC as a cross-sectional network, integrated early into early cancer care.

**PALLIATIVE CHEMOTHERAPY**

Four principles guide palliative chemotherapy: therapy (1) with the fewest side effects, (2) with evidence base for relieving cancer symptoms, (3) with the greatest chance for improving quality of life, and (4) with evidence for extending quality of life (see sidebar).

**MAINTAINING HOPE**

Maintaining hope in incurable cancer is difficult. There are ways of doing this. Communication style is as important as what is communicated. Sit with the patient and be willing to share yourself. Query patients about psychosocial concerns and their experience with cancer. Be sensitive to emotive words and respond with empathy. Do not distance yourself and be mindful of your thoughts and feelings. Do not use false reassurance. Answer questions honestly and compassionately. Check their understanding of prognosis and whether they want it in qualitative or quantitative terms. Be willing to provide the information they want when they want it. Offer the most up-to-date therapy where appropriate. Discuss outliers who do better than anticipated, but do not make outliers the rule. Facilitate coping through open discussions about fears, anxiety, and concerns. Emphasize options and a willingness to discuss complementary therapies, second opinions, and potential future scenarios.

**SIDEBAR: Discussing Palliative Chemotherapy and Targeted Agents**

- Ask what the patient wants to know about the natural history of their cancer.
- Anxiety will need to be addressed before prognosis.
- Patients should be told that the intent of treatment is not curative.
- Outline course of palliative anticancer therapy.
- Use validated measures of symptom palliation as you do for tumor response.
- Discuss that less antitumor therapy may be more in terms of quality and quantity of life.
- Discuss response rates, how it is measured, and usual duration of response.
- Mention one negative piece of information. This will improve the patient’s understanding of prognosis and options (although many respond, a substantial minority do not benefit from this therapy).
- Use decision aids to facilitate understanding.
- Introduce reasonable alternatives before a final decision is made.
- Reflect on previous experiences with palliative therapies. Did therapy improve symptoms and quality of life or lead to adverse events and hospitalization?
- Move hope from therapy to personal goals.

**THE IMPORTANCE OF EARLY INTEGRATION OF PALLIATIVE CARE FOR ADVANCED CANCER: A MEDICAL ONCOLOGIST’S PERSPECTIVE**

**Decreased Time, Increased Demands**

In the past two decades, understanding of the molecular pathways and biologic subtypes of cancer has been rapidly translated into improvements in oncology treatments and outcomes. This understanding has been paralleled by increased complexity in diagnostic and therapeutic algorithms, and acceleration in the pace at which algorithms or guidelines have been revised. Further, regulatory and reimbursement requirements encountered in providing clinical care and conducting clinical research have also grown exponentially, increasing time that oncologists and investigators spend between and during clinical encounters that are unrelated to patient-centered care. The average medical oncology visit was recently estimated to be 24.7 minutes and has become shorter in care settings where capitation or performance-based compensation are in place.

Within this changing care environment and increasing time limitations, paradoxically the multidimensional needs of a patient on therapy for advanced cancer will increase. For example, the immediate implication of modest improvements in overall survival afforded by targeted therapy are longer durations in which patients experience many physical symptoms and psychosocial distress related to living with advanced cancer. At least in theory, burdens on caregivers will increase with this evolution. Additionally, targeted therapies have resulted in the development of syndromes associated with “off and on target toxicities,” which demand their own expertise to manage.

**A Disconnect between Supply and Demand**

In the last three decades, advances in SPC have led to standardization of the subspecialty, with board certification in 2008. A recent survey of cancer centers found various palliative care services available within 98% of National Cancer Institute (NCI) cancer centers and 78% of non-NCI cancer centers. Nevertheless, a disconnect occurs between increasing demand for SPC by oncology practitioners and patients, the growing availability of these services, and referral patterns of oncologists for these same services. For example,
only approximately 13% of respondents in a recent survey of Canadian oncologists regularly referred patients to SPC if the prognosis was more than 6 months and a substantial proportion did not refer patients with uncontrolled symptoms if prognosis was more than 1 year.28 In a survey by the European Society of Medical Oncology, only a minority frequently collaborated with SPC.27

Benefits of Early Integration
Simultaneous care models and early integration of SPC with cancer therapy has been demonstrated to be feasible in phase I and II trials of investigational agents,43 and during the course of standard systemic or radiation therapy for newly diagnosed advanced no–small cell carcinoma.44 More recently, Temel et al. found that a study of early integration of a palliative care intervention within 8 weeks of the diagnosis of lung cancer for patients receiving systemic therapy met its primary endpoint of improved quality of life in the intervention group measured at 12 weeks.7 Although not controlled for “clinical attention” received in the intervention group, a compelling secondary finding of this study was a 2.7-month significant improvement in median survival with integrated SPC despite decreased aggressive EOL cancer care and earlier referral to hospice (p = 0.02).7

This survival advantage reviewed in the context of six other randomized controlled trials of palliative care interventions in patients with and without cancer (but all with serious illnesses) prompted ASCO to issue a Provisional Clinical Opinion, advising that standard oncology care with SPC should be considered early in the course of metastatic cancer or for patients with high symptom burden.45 The benefits for this recommendation are intuitive to most clinicians: improvements in symptoms, quality of life, patient satisfaction, and caregiver burden across these randomized trials. No trial has shown harm in the form of inferior survival outcomes or excessive cost with SPC.

Harms of Late Referral
Harms associated with late referral to SPC and poor communication around EOL decision making may not be appreciated by clinicians. Within the control arm of the Temel study, those not receiving SPC had a substantially higher incidence of aggressive EOL cancer care, defined as chemotherapy within 14 days of death, no hospice care or admission to hospice within 3 days of death.7 In a longitudinal cohort study of patients with advanced cancer and their caregivers, patients not reporting EOL discussions had significantly higher rates of aggressive EOL cancer care, which was associated with worse quality of life rated by caregivers in postmortem interviews (p = 0.02).46 Systematic reviews demonstrated complicated bereavement for surrogates at EOL, particularly when patient preferences are not communicated in advance.47 Caregiver outcomes, traditionally beyond the scope of medical oncology, are important to both clinical care and research within SPC. Aggressive EOL cancer care and death within an ICU or hospital (as compared to home hospice) has been associated with worse bereavement adjustment, including postmortem depression, post-traumatic stress disorders, and protracted grief disorders.46,48

Many Barriers Represent Opportunities
Overcoming institutional and financial barriers to early integration of SPC, discussed elsewhere, will require development of consensus among stakeholders and structural changes. Physician and patient-related barriers are amenable to pragmatic solutions49 that address specific concerns and represent a mixture of definitional issues, sociocultural factors, knowledge deficits/insufficient training, and a historic lack of collaboration between the two disciplines (Table 1).

### TABLE 1. Physician- and Patient-Specific Barriers to Frequent and Early Integration of Palliative Care with Standard Oncology Care

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Potential Solution</th>
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<tbody>
<tr>
<td>Physician’s discomfort with palliative care.</td>
<td>Rebranding names to supportive care to avoid associations with EOL care.</td>
</tr>
<tr>
<td>Physician’s perception that patients have negative attitudes toward “palliative care.”</td>
<td></td>
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<tr>
<td>Intercultural50 and intracultural variability in prognostic information and patient choices to receive prognosis; respect for autonomy.</td>
<td>Cultural competency and access to psychosocial oncology specialists with expertise in nuanced communication. The majority of patients want to know their prognosis; doing so allows planning and establishing medically appropriate goals and does not squash hope.</td>
</tr>
<tr>
<td>Insufficient training and “learned helplessness.”25</td>
<td>Integration of palliative care into medical oncology fellowships, incorporate institutional proficiency standards related to pain management and core curriculum into clinical staff credentialing. Where resources are limited, use SPC consultants as educational resources.</td>
</tr>
<tr>
<td>Compassion fatigue and unprocessed grief.25</td>
<td>Enhancement of physician’s communication skills around EOL conversations, institutional psychosocial support to prevent burnout.</td>
</tr>
<tr>
<td>Concern that palliative care physicians lack sufficient oncology background to counsel patients about treatment decisions.</td>
<td>Increased collaboration between medical and SPC in clinical care and research activities, participation of SPC in tumor boards, multidisciplinary clinics.</td>
</tr>
<tr>
<td>Ambivalence among referring physicians as to who should coordinate palliative care.</td>
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CONCLUSION
A rate-limiting step to the universal early integration of subspecialty palliative care services is the availability of dedicated outpatient SPC clinics, but flexible and pragmatic approaches to physician- and patient-based factors have demonstrated potential in moving toward this ideal. True integration and collaboration will involve recognition of the heterogeneity of oncologist role identification and interests. A survey of academic oncologists found that some oncologists view their role primarily in biomedical terms, whereas others prefer a biomedical and psychosocial role.\(^5\) It is hypothesized that those with broader role identification might value a more active role in communication around EOL decisions and in providing EOL care. Finally, it is worth noting that although repeated observation of physician discomfort with the term palliative care and its historic roots can be viewed as a “barrier,” it is likely also a testament to the close and engaged relationship that oncologists forge with their patients in the face of incurable cancer.

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The author(s) indicated no potential conflicts of interest.

References


ETHICS

What Is Professionalism in the Era of Personalized Global Cancer Care? Bridging What We Say, Teach, and Do

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Professionalism in Global, Personalized Cancer Care: Restoring Authenticity and Integrity

Antonella Surbone, MD, PhD

OVERVIEW

Personalized medicine is revolutionizing cancer care and creating new expectations among oncologists and patients. At present the benefit is still marginal, however, and must be understood as incremental. In addition, cultural and resource disparities limit the sustainability of new cancer therapies on a global scale. Adequate instruments are needed to enable our exercise of sound and honest judgment in distinguishing breakthrough treatments from those that yield only marginal or doubtful improvements, and to develop strategies for formulation and correct application of balanced guidelines for sustainable cancer care. Professionalism requires that the acquisition of knowledge and skills go hand in hand with moral education in the intellectual virtues of humility, perseverance, adaptability, communicativeness, and commitment to resist self-deception or conflicts of interest. Hidden curricula undermine the moral values of medicine: these must be understood and uncovered. We should possess a special body of knowledge, skills, and values that allow us to change our practices when appropriate and to be stewards of society’s limited resources through proper communication with our patients and families. In the era of personalized oncology and global issues of sustainability, professional authenticity and integrity in cancer clinical practice are key to bridging the gaps between true and false expectations of patients and the public.

Because of the nature of the patient-doctor relationship, an asymmetric relation of help, physicians are bound by an oath to respect the virtues and values of medical professionalism and to act accordingly. Professionalism is defined by Merriam-Webster as “the conduct, aims, or qualities that characterize or mark a profession or a professional person.” Medical professionalism is founded on individual characteristics and values, but also relates to contextual factors such as organizational support, workplace, others’ expectations, and the specifics of each patient-doctor encounter. Professional competence is the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and community being served. The primacy of patient welfare, patient autonomy, and social justice was stressed in the “Medical Professionalism in the New Millennium: A Physician Charter.” The American Society for Clinical Oncology (ASCO) past president Jim Armitage added that professionalism in oncology requires “maintaining trust by managing conflicts of interest” especially through proper relationships with the pharmaceutical industry. Maintaining “the respect and trust of our patients and the general public will determine our ability to influence rational decisions about the practice of oncology at all levels.”

Traditionally, three main features define the medical profession: 1) extensive training; 2) training that involves a notable intellectual component; and 3) a trained ability that provides an important service in the community. Through the process of training, certification, credentialing, and re-credentialing, physicians acquire knowledge and professional skills, along with responsibilities and the ability and right to exercise autonomous discretionary judgments. Oncologists dedicate substantial time to reading journals, searching the literature to illuminate particular cases, attending meetings and conferences, and pursuing academic interests. Intellectual stimulation and excitement are important resources to enhance satisfaction and prevent or counteract burnout. Many oncologists have broader social interests and responsibilities than those limited to the care of individual patients and engage in community activities. They include helping to prevent illnesses and improve health care levels and awareness of medical issues through education.

CANCER AS SOCIAL ILLNESS AND COST SUSTAINABILITY

According to the Union for International Cancer Control (UICC), more than half of the deaths from cancer (55%) occur in the less-developed areas of the world. By 2030, it is expected that around 60% to 70% of all new cancer cases will occur in developing countries. According to the World Health Organization (WHO), about a third of all cancer...
deaths are a result of modifiable risks, such as tobacco use, obesity, harmful use of alcohol, and infections. In addition, many cancers can be prevented through screening, such as cervical cancer, and with vaccination against hepatitis B virus and human papillomavirus. The early detection of many cancers, including breast, cervical, and colorectal cancers, can also result in successful cures.

More than 50% of countries worldwide are struggling to prevent cancer and to provide treatment and chronic care to patients with cancer, as demonstrated by a recent survey conducted by the WHO, which funds development of cancer registries in developing countries to provide information on the cancer burden and help their governments plan prevention and treatment strategies. ASCO will expand the scope of its international programs and double funding by providing oncology instruction for non-specialists, offering mentoring, and providing grants for research into cancer-control strategies.

Sustainability of health care costs is decreasing in western countries, while inefficiency and waste increases. The American Board of Internal Medicine Foundation has issued the “Choosing Wisely” campaign and the American College of Physicians has implemented a “High-Value, Cost-Conscious Care” initiative to guide physicians. The Accreditation Council for Medical Education in the United States mandates that training for physicians incorporate “considerations of cost awareness” into practice. Yet most residency programs still lack curricula in this area. A case-based curriculum for internal medicine residents has been developed at University of California, San Francisco, linking cost awareness and evidence-based diagnosis with the treatment of common diseases through discussion of clinical scenarios. Training on how to integrate cost consciousness with quality and efficacy of care should also be offered to oncology fellows.

PERSONALIZED ONCOLOGY
The aim of personalized oncology is to treat patients with therapies targeted at specific tumor characteristics, such as those developed for HER2-receptor positive breast cancer. Personalized medicine is revolutionizing cancer care and creating new expectations among oncologists and patients. These expectations are often difficult to meet, especially in view of limited health care resources in both developing and industrialized countries. In addition, today’s cancer research and care, focused on evidence-based and personalized medicine, tends to exaggerate public and professional expectations of oncology care, potentially creating a credibility gap.

Personalized medicine, in fact, is still in an early stage of development and implementation, and oncologists, teachers, and associations must fill the credibility gap through communication with individual patients and families, as well as through education of the public and of oncologists in training. The European Society for Medical Oncology, on the occasion of the 2013 World Cancer Day, supported dispelling the myth that personalized medicine is “already a reality for all cancer types and all patients with cancer.” On one hand, oncologists are duty bound to raise awareness of new treatments’ high potential and to guide their patients in gaining access to them through clinical trials. On the other hand, they also must bear in mind the importance of open communication with patients with cancer about the limitations and uncertainties of personalized oncology and targeted therapies. Furthermore, limited economic resources place constraints on cancer therapeutics worldwide. Because severe financial burdens are imposed on many patients with cancer and their family caregivers, we need to learn how to communicate properly and ethically about treatment costs. Discussing and offering affordable treatments to our patients and refraining from perpetuating false hopes about new treatments with marginal or doubtful improvements will help us maintain fairness and equity in our practices, while enhancing our credibility will help patients and others.

KEY POINTS

- Professionalism in oncology is sustained by sincerity, accuracy, authenticity, and integrity.
- Personalized medicine is revolutionizing cancer care and creating new expectations among oncologists and patients, yet present benefits are still marginal and must be understood as incremental.
- Existing gaps in knowledge and sustainability of new anticancer therapies need to be bridged on a global scale.
- Acquiring adequate instruments and exercising sound judgment about new treatments are key to professionalism in oncology.
- Unmasking hidden curricula in training is needed to bring to the forefront our professional integrity and restore the public image of our profession.

PROFESSIONALISM IN THE ERA OF PERSONALIZED ONCOLOGY
In view of the developments of genomics and personalized oncology, professionalism requires reframing the expectations of professionals, patients, and the public in order to enhance the credibility, trust, and sustainability of what we say and what we do. In our profession, the acquisition of knowledge and skills go hand in hand with moral education. A key element of professionalism in oncology is the acquisition of adequate instruments to support our exercise of sound and honest judgment in distinguishing breakthrough treatments from those that yield only marginal or doubtful results. Such an approach is also needed for development of strategies to formulate and apply balanced guidelines for sustainable cancer care.

Over the past few decades, evidence-based medicine (EBM) has prevailed, yet the original notion of evidence now seems to be too narrow as regards patient-centered, personalized, global oncology. EMB was defined by one of its founders, David Sackett, as “the explicit, conscientious, judicious
use of current, best evidence in making decisions about the care of individual patients. It means integrating individual clinical expertise with the best available external clinical evidence from systematic research.9 By questioning, searching, appraising, applying, and evaluating (the five steps of EBM), physicians can better answer clinical questions and develop appropriate mindsets and new skills.

The culture of EBM flourished in contradistinction to traditional medicine, as a new paradigm for medical practice “de-emphasizing intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research.”10 Accordingly, EBM appears to focus only on clinical decision making while it should be part of a larger “underlying geography” of medicine as a discipline seeking to expand the scientific understanding of human diseases and to develop new, more effective therapies, while, at the same time, attending to population and individual global well-being.11

In EBM, decision making is based on ranking evidence, and the gold standard for evidence is that obtained from randomized controlled trials (RCTs).12 These are an essential tool for the advancement of clinical oncology, but they must be integrated with other approaches to make their results applicable to heterogeneous patients populations. Furthermore, although randomization assures that treatment groups are closely matched for important variables, within each treatment group there may be subsets of patients who are “responders” or “non-responders” because they carry a specific gene mutation, are exposed to specific environmental influences, or for whom there are distinct underlying causes for the identified disease. Thus, a narrow understanding and use of EBM and RCTs may hinder, rather than favor, the progress of personalized oncology.

To overcome some of these limitations, a novel medicine-based evidence approach has been recently proposed.13 This approach moves beyond evidence-based medicine by emphasizing not only the validity and generalizability that determine the accuracy of RCTs, but also clinically relevant issues about patients, treatments, and outcomes. In contrast to EBM, where the emphasis is on hierarchies of research design, the new medicine-based evidence approach is both rigorous and patient-centered in that it calls for studies to be reviewed systematically in regard to patients, treatments, and outcomes, and for the integration of medical and psychosocial aspects of clinical care.14

Guidelines are not meant to replace the art of medicine but to help define the circumstances in which a therapy is more likely to be beneficial or harmful, and to delineate boundaries around decisions that are patient sensitive.15 According to the Institute of Medicine, high-quality systematic review is a cornerstone of guideline development, but it may not be enough for those areas of medical uncertainty where evidence is limited or poor, as is often the case for treatment decisions regarding patients with cancer with multiple comorbidities, as RCTs generally exclude such patients. Treatment decisions should be based on evaluation of benefits compared with harm as derived from evidence, but also on patient preferences and on oncologists’ best judgment regarding medical and contextual aspects of the patient’s illness.14-16 In the absence of good evidence with regard to comorbidities, for example, decisions are more difficult and tend to rely on the subjective evaluation of the oncologist that could include biases or prejudices toward elderly, underprivileged, or minority patients with cancer, who are frequently affected by comorbidities in virtue of socioeconomic and cultural factors. Guidelines are generally translated into algorithms for care and become components of medical education. Professionalism requires that we teach how to interpret and apply these algorithms correctly and justly.

PROFESSIONALISM AND HIDDEN CURRICULA

The medical profession portrays itself as a purely scientific, altruistic public service that pursues high ideals and goals. Yet on a day-to-day level, practicing medicine necessarily involves self-interest and practice patterns that are not always evidence-based or personalized. In addition, according to Hafferty and Franks, most of the critical determinants of physician identity occur not within the formal curriculum, but through more subtle, less officially recognized, “hidden curricula.”18 A hidden curriculum is transmitted through role modeling and institutional cultures about constitutive elements of the medical profession, such as what is considered to be “real” diseases, what symptoms are important, and what brings esteem to physicians within their profession. The overall process of medical education is presented as a form of moral training of which formal ethics instruction constitutes only one small piece. What is taught through hidden curricula is often “antithetical to the goals and content of courses formally offered” to students and fellows, resulting in the progressive decline of moral reasoning and erosion of empathy that many studies have documented to occur during medical school.19 Because medicine is not a value-neutral enterprise, “medical training above all else involves the transmission of a distinctive medical morality.”18 Medical students and fellows not only acquire knowledge and behavior rules, but also learn more essential aspects of professionalism such as how to feel about uncertainty and failure, how to communicate bad news, and how to address cross-cultural differences or handle medical mistakes. They learn how to be doctors through a process of socialization that involves their character and identity as professionals, which should be based on a restoration of authenticity and integrity.

Almost every medical professional body in North America considers professionalism to be an essential topic and has mandated that it be taught in faculties of medicine. The Accreditation Council for Graduate Medical Education, responsible for accrediting residency and internship programs in the United States, considers it a core competency. Some medical schools and residency programs have acknowledged the existence of hidden curricula and accepted responsibility for both understanding and modulating the effects of these curricula on students’ knowledge, skills, and
values. Uncovering hidden curricula is a first step to restoring professional behavior and practices that are authentically caring.\(^20\)

Introducing medical humanities in medical school curricula can also foster moral qualities in medical students and oncology fellows. A Robert Wood Johnson Medical School study found that a longitudinal experience involving “blogging about clerkship experiences, debriefing after significant events, and discussing journal articles, fiction, and film” raised empathy scores.\(^21\) Through the humanities, medical students become more self-aware and open to others, develop better critical analysis capacities, and familiarize with the coexistence of different, often conflicting, views of illness, suffering and dying. Learning about the experiences of oncologists who have become patients with cancer is also an invaluable tool for develop or restoring empathy.\(^22\)

**AUTHENTICITY AND INTEGRITY IN MEDICAL PROFESSIONALISM**

Professionalism in the era of personalized oncology and global issues of sustainability needs to be sustained by our sincerity, accuracy, authenticity, and integrity. Accuracy implies doing the best one can to acquire true beliefs and sincerity requires revealing through communication what one really believes.

For philosopher Bernard Williams, “one component of the virtue of accuracy lies in the skills and attitudes that resist the pleasure principle, in all its forms, from a gross need to believe the agreeable to mere laziness in checking one’s investigations.”\(^23\) Sincerity is a matter of disposition in the context of a relationship that involves the sense of justice and of trust. Williams writes, “We want people to have a disposition of sincerity which is centered on sustaining and developing relations with others that involve different kinds and degrees of trust. "Authenticity is a more "personal" virtue, related to personal identity. In an existential perspective, authenticity reminds of “transparency” with regard to one’s situation and the recognition that one can be responsible for who he or she is.”\(^23\)

Integrity, from the Latin *integritas* (wholeness), is defined as adherence to moral and ethical principles, soundness of character and honesty, and also as being whole, entire, and undiminished. Persons of integrity stand up for their best judgment about what is worth doing in life while showing proper respect for the judgment of others. Integrity also involves self-monitoring, whereby a person examines her moral emotions, including regret, remorse, guilt, shame, and others, much like in the “examined life” of ancient Greek philosophers. Despite some views of professional integrity as a weaker form of morality, more similar to etiquette, medical professionalism requires that we have both intellectual and personal integrity in caring for our patients. Oncologists should possess the intellectual virtues of humility, perseverance, adaptability, and ability to communicate, as well as a commitment to resisting commercialization of research, self-deception, or conflict between the free pursuit of ideas and their responsibility to others and to putting their patients’ good first.\(^24\) Furthermore, possessing a special body of knowledge, skills and values, and given sound evidence, we can improve our practices through accuracy, sincerity, and authenticity, while also restoring our own and others’ confidence in our integrity.\(^25\)

According to Hafferty, there is a meaningful and measurable difference between acting professionally and being a professional, for it is possible to behave professionally without having authentically internalized core values. Yet in medical education, we must send a message that authenticity and integrity are matters of great concern. We must also assure that the learning environments of our students support professionalism as medicine’s commitment to being a moral community.\(^26\) Teachers are extremely important in the education and training of young physicians and oncologists. Excellent clinical teaching transcends ordinary teaching by being multifactorial and characterized by inspiring, supporting, actively involving, and communicating with students. Teaching the teachers should focus on development of the noncognitive attributes of clinical instruction such as values and emotions, as well as the knowledge and skills associated with effective teaching.\(^27\)

**CONCLUSION: BRIDGING GAPS**

Personalized medicine is revolutionizing cancer care and creating new expectations among oncologists and patients. However, at present the benefit is still marginal and must be understood as incremental, and cultural and resource disparities limit the sustainability of new cancer therapies on a global scale. Current teaching and training, often through the hidden curriculum of oncology, reinforces the myths of genomics and personalized medicine and does not prepare oncologists to address the sustainability of personalized medicine with patients and the public. The gap between the high ideals of the medical profession and the realities of training and practice may lead to cynicism in both the profession and the public.

There are few safe spaces to discuss the gaps between what we say and what we teach, on one hand, and what we do as cancer care specialists, on the other. Professional image and iconic public status make it difficult to deal with the challenges of modern cancer research and care, which tend to exaggerate public and professional expectations of oncology. We must encourage oncologists’ critical and independent analysis of new knowledge, as well as open communication with patients with cancer. Oncologists’ knowledge is translated in prescriptions, recommendations, and advice that strongly influence the patient’s choices and outcomes. Raising exaggerated or false expectations is disrespectful to truth itself and, especially, to patients with cancer who are destined to die, often after long periods of struggling and suffering, or who may not be able to afford expensive therapies. Honesty and humility must inform how we talk about the profession with patients and the public, particularly in the increasingly international and cross-cultural settings of contemporary oncology care.
Professionalism rests on physicians’ inseparable epistemic and ethical commitment to the patient-doctor relationship. Recognizing human propensity for cognitive bias, medical teaching should foster “metacognition”—the ability to overseeing one’s own thinking while also recognizing and preventing systematic errors.28 Stories are also an essential part of how individuals understand and use evidence. Contrary to what is often assumed, narratives can link individuals and their experiences to evidence and become tools to make science more easily comprehensible, without introducing anecdotal bias.29 In the era of patient-centered personalized medicine, a narrow perspective of what constitutes “evidence” is no longer tenable or effective. Empowering oncologists with time and skills to evaluate research by blending evidence and judgment can help them fill performance gaps in oncology practice and ultimately improve public health.28 Furthermore, possessing a special body of knowledge, skills and values allows oncologists to change their practices out of accuracy, sincerity and authenticity, thus restoring confidence in their professional integrity.25

Professionalism requires also the ability to be stewards of society’s limited resources, so that they are not misplaced or wasted.30 Professional authenticity and integrity in cancer clinical practice are key to bridging the gaps between true and false expectations of patients and the public with regard to today’s feasibility and sustainability of personalized oncology.

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References

Communication in View of Limited Resources: International Perspective

Matjaz Zwitter, MD, PhD

OVERVIEW

Low socioeconomic status is associated with several risk factors for cancer, including a higher risk of presentation with advanced and often incurable disease. Treating patients in areas with limited resources requires not only the goal of saving or prolonging life, but also to alleviate suffering, including physical, emotional, and social components. Because complete coverage of all costs for modern cancer management by local institutions or governments is not possible in most (if not all) areas, most patients with cancer have to contribute toward the costs of their treatment. However, the demand for financially sustainable health care leads to restrictions in the spectrum of available treatments and often results in the creation of waiting lists for people requiring treatment. Communication between patients and providers in such circumstances is often challenging, especially when coupled with patients who have limited or no health care insurance and/or lack any ability to pay for services. Ultimately, any treatment plan should take into account the risks, benefits, personal goals, and beliefs of the individual with cancer. In areas of limited resources, the financial burden of treatment placed on the patient and his or her family must also be a part of the conversation and decisions regarding therapy. Within these parameters, sharing information and options becomes an indispensable condition for communication and the foundation of trust in the doctor-patient relationship.

Cancer affects people regardless of education, race, socioeconomic status, marital status, or religion. Proper communication adjusted to the needs of the individual is a prerequisite for a balanced discussion of the diagnostic and treatment possibilities.

CANCER IN THE SETTING OF LIMITED RESOURCES

For providers caring for patients in underserved or minority communities and/or in areas with limited resources, risks and benefits of all treatments should be balanced by a consideration of the fiscal burdens that may be placed on the patient and his or her family, especially when the evidence to support more expensive treatments may not exist. Communication is an important element of cancer care for patients with limited resources.

Several factors contribute to the burden of cancer among people living in low-resource areas (Table 1). These include various factors such as lifestyle (increased rates of smoking and use of tobacco products and a higher incidence of alcohol use), societal (pollution exposures in the working place), social (sexual promiscuity, drug use), and other factors (including bilharziasis and untreated chronic infections, such as infection with *Helicobacter pylori*).

In addition, once detected, cancer in individuals from low-resource areas is often diagnosed in advanced stage. Factors responsible for this common observation may include less access to health care and/or screening. This too may be interrelated to other issues, such as lower educational levels, literacy, and a lack of basic information about detecting early signs or symptoms. In places where access is limited, financial constraints can also explain the tendency toward a more advanced stage at diagnosis, especially when an individual feels he or she cannot go for an evaluation for fear of loss of employment.

In addition to the sociodemographic factors that increase the risk of an advanced cancer diagnosis in patients from limited-resource areas, the economics of cancer plays a role in the outcomes of these patients. The selection of treatments, both from a country-specific and patient-specific perspective, is highly variable and depends very much on costs in relation to benefits and adverse events of newer agents.

Unfortunately, these economic disparities often play out by physicians. For example, to patients with limited health care insurance and to those who cover the costs using personal or family savings, physicians may not offer a more extensive work-up as would be routine if costs were not an issue (e.g., the use of PET-CT). Likewise, physicians may not raise the options of newer (and hence, expensive) treatments, offering instead therapy they know will be more affordable. The interplay between fiscal burden and cancer treatments are not
TABLE 1. Risk Factors for Cancer in Patients from Low-Resource Areas

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Cancer types</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking</td>
<td>Lung, head and neck, bladder</td>
</tr>
<tr>
<td>Pollution at work and in the environment</td>
<td>Lung, bladder</td>
</tr>
<tr>
<td>Asbestos</td>
<td>Mesothelioma, lung</td>
</tr>
<tr>
<td>Alcohol</td>
<td>Head and neck, esophagus</td>
</tr>
<tr>
<td>Poor dental and oral hygiene</td>
<td>Head and neck</td>
</tr>
<tr>
<td>Chewing of tobacco and of other addictive substances</td>
<td>Oral cavity</td>
</tr>
<tr>
<td>Hepatitis B carriers</td>
<td>Liver</td>
</tr>
<tr>
<td>Poor sexual hygiene and HPV viral infections</td>
<td>Cervical</td>
</tr>
<tr>
<td>Poor nutrition and untreated chronic <em>H. pylori</em> infection</td>
<td>Stomach</td>
</tr>
<tr>
<td>Bilharasis</td>
<td>Bladder</td>
</tr>
<tr>
<td>Chronic malaria in combination with Epstein-Barr viral infection</td>
<td>Endemic Burkitt lymphoma</td>
</tr>
<tr>
<td>Obesity</td>
<td>Breast</td>
</tr>
</tbody>
</table>

soley due to physician judgment, however. Patients may also be forced to make choices about supportive care and therapeutic treatments in light of limited resources, including foregoing treatment with pain medications, antiemetics, and suggestions for nutritional supplements or dietary instruction. In most instances, these factors may result in worse outcomes, including survival.2-6

REducing Disparities Among Patients With Cancer

The efforts to reduce disparities among patients with cancer and to improve the prospects for the deprived patients vary widely, depending on the economic position of a country, recognition of cancer as a pressing health problem, and the system of national health care. The spectrum of activities directed toward improved outcome for patients from deprived populations ranges from total ignorance to active programs. A comprehensive review of the situation worldwide would be clearly out of the scope of this chapter. Nevertheless, a few examples from different parts of the world are presented to illustrate the situation.

In Europe, the European Society of Medical Oncology (ESMO) included reduction of disparities in its Medical Oncology Status in Europe Survey (MOSES). This document stresses the importance of reducing disparities in the quality of care available to patients in different parts of Europe. While the emphasis is on access to state-of-the-art diagnostics and treatment for all patients with cancer, less attention is devoted to special measures directed toward vulnerable groups from areas of society where affording these measures is more doubtful.

Disparities in cancer care and outcomes have been much more clearly analyzed by ASCO. Cancer health disparities for racial and ethnic minorities have been thoroughly presented.6 Key components of the commitment of ASCO are enhancing awareness of disparities; improving access to care; and supporting research on health disparities.9 Finally, ASCO realized that the question of suboptimal approach to disadvantageous populations is a global, rather than national, problem and launched an initiative to address this question on a larger scale.10

While discussions on disparities in cancer care in developed countries focus mainly on access to modern diagnostics and treatment, the situation is totally different in developing countries. Since more than 80% of cancers are diagnosed in advanced stage, the list of priorities includes tobacco control and reduction of other causative factors, early detection of breast and cervical cancers, and palliative treatment. In these areas, the utilization of resources to pay for contemporary anticancer treatment is not a priority.11 Looking from the perspective of national politics, such a rational policy is justified. Nevertheless, this position entirely ignores the objectives to approach patients with compassion: even in India, patients and their families are aware of the new developments in cancer care and wish to share the benefits of modern oncology, although often it is beyond their reach.

KEY POINTS

- Physician empathy and patient trust are two essential components of sincere communication.
- Disparities in access to care exist internationally; patients with cancer who come from low-resource areas are more often diagnosed with later-stage disease, receive less than optimal anticancer treatment, have less access to supportive measures, and worse survival outcomes.
- In some clinical situations, the evidence does not support the use of newer and more expensive treatments compared to lower-cost treatments.
- In the determination of treatment plans, the risk and benefit of all options should include a consideration of fiscal burden, particularly when the resources of the individual patient and their family are limited.
- An honest and open dialogue built on knowledge and mutual respect is the foundation of cancer therapy in limited-resource areas.

HEALTH CARE AND COMMUNICATION WITH PATIENTS WITH CANCER

Virtually no country can afford 100% coverage of cancer care (starting from work-up to end-of-life) for all citizens. Therefore, even the data obtained from important randomized trials, which may change the standards of care for any given disease type, should be evaluated at the local level. Critical review is essential to ensure that the data have been sufficiently vetted and that the findings are relevant to the specific group for which we are caring. Sometimes, especially in areas of limited resources, the benefits of treatment does not
outweigh the currently applied (albeit less temporary) treatments, nor can they justify the costs. Such a decision is of even greater importance when diagnosis of cancer may herald a financial disaster for the patient and his or her family.

Restrictions in access to cancer diagnostics and treatment, in one form or another, are a reality for the large majority of patients with cancer worldwide. It is likely that more than 90% of patients with cancer either have to personally cover at least some of the costs of cancer management or feel restrictions to accessing care imposed by their national or individual health care provider. When speaking about resources, availability of treatment, and the role of economic factors for communication, at least three different situations should be distinguished: (1) approach to patients in national health care systems based on solidarity and offering more or less free care to all patients with cancer; (2) patients who have individual health care insurance with limitations regarding the coverage of particular costs; and (3) patients without health care insurance, both in developed and developing countries.

According to European tradition, application of the ethical principle of justice to health care is understood as the right of every citizen to receive health care according to his or her needs. Decent health care is therefore considered a basic human right. Most European countries, Canada, and some other non-European countries are proud of such a system. In health care systems based on solidarity, nobody is left without some degree of health care. While this appears to be an ideal solution, there are problems with its implementation.

In order to meet any mandate about complete coverage of health care costs for every patient with cancer, the question of controlling expenses becomes an important issue and rises to the surface. The National Institute for Health and Clinical Excellence (NICE) in England is an example of an institution that was developed to evaluate new proposals for treatment. The good aspect of such a system is that it offers decent care to all citizens, regardless of their social status, and is financially sustainable. However, the “careful evaluation” may result in delays, sometimes considerable, in approval of new treatments. Some treatments, such as addition of bevacizumab to platin-based chemotherapy for advanced non-small cell lung cancer, have never passed the NICE approval. In such cases, NICE has been able to save substantial resources to the National Health System, but has resulted in a lack of access to these agents in the United Kingdom, sometimes for years after they have been registered in continental Europe.

Patients in many other countries with national health care systems face different problems in access to modern medical care. If money is scarce and limitations regarding the spectrum of approved methods are not very strict, waiting lists for diagnostics and treatment are unavoidable. Waiting lists for cancer diagnostics and treatment are therefore a reality in many countries with declared free universal medical care.

What are the implications of these factors for communication? Because cancer is no longer taboo in most parts of the world, and news about new medical achievements are easily accessible via various media outlets and on the Internet, a paternalistic approach to patients is no longer possible. This leads to an increasing tension between physicians on one side, faced with a limited armamentarium of agents that can be used, and patients and their relatives on the other, who might demand access to the agents recently approved elsewhere.

**LIMITED HEALTH CARE INSURANCE**

Patients with limited health care insurance come from all parts of the world, including most developed countries, like the United States, and developing countries, like India, where a proportion of population has individual health care insurance.

Limited insurance usually provides for the basic costs of diagnostics and treatment. However, the insurance may not cover expensive procedures such as sophisticated surgery, modern radiotherapy, bone marrow transplantation, or targeted drugs.

To their disappointment, many of these patients realize the limitations of their health care insurance only after a serious disease such as cancer is diagnosed. Information on limitations and on the need to contribute to the costs of treatment therefore comes as a shock to the patient and to his or her family and adds to the burden of diagnosis of a malignancy. Sincere communication with the oncologist is essential to resolve the financial issues and find an acceptable plan for treatment. Suggestions for physicians are offered in the last section of this chapter.

**PATIENTS WITHOUT HEALTH CARE INSURANCE**

Some individuals without health care insurances come from developed countries without a universal national health care system. In addition, a large number of individuals from developing countries do not have any health care insurance.

In general, these patients come from the socially and economically underserved parts of society. A vulnerable patient, one with advanced cancer and without proper health care insurance, cannot manage all incumbent problems: the physical and emotional burden of the disease, decisions regarding proposed treatment, and financial issues for themselves and their family. Additional obstacles may include limited literacy and limited education regarding the biology and approach to cancer. Due to the often weak or nonexistent basic medical care network for general practitioners coupled with the inability to prescribe effective treatments (because of fiscal constraints), sometimes an oncologist’s only option is to arrange supportive and home care.

Some would argue that costs of a proposed treatment are not an issue to be considered by a physician, and that it is the patient who should decide the price they are willing to pay. Such an opinion is based on a patient’s full autonomy. However, to take this position ignores what is often the reality of patients and providers in limited resource areas; that the treatments that could be offered cannot be realistically obtained.
For such patients, emphasizing the prognosis in terms of curability can be one of the best ways to communicate both the limitations of treatment and the ways to move forward, whether by emphasizing symptom control or moving toward supportive care. We as physicians know how broad and ill-defined the border is between curable and incurable cancer, and how unrealistic the expectations of our patients may be, despite all explanations regarding the prospects of their disease. Hence, it is our duty to help communicate information so that shared decision making can take place and a mutual understanding reached.

CONCLUSION

Diagnostics, treatment, and communication are the three pillars of the medical practice. It is often said that communication is a process which takes time, rather than a single event. As such, education and training in communication are important and should not be limited to communication skills acquired during medical training in diagnostics and treatment.

Many patients may not wish to make decisions and would rather trust their physician. This may be the case in situations where family and community connections are often valued more than individual autonomy. A recently published book on communication, with authors from all parts of the globe, offers a deeper insight into the questions of patient’s autonomy and its dependence on cultural and social factors.

The New England Journal of Medicine has published dozens of thoughtful papers on health care reform in the United States. While any attempt to summarize widely diverging views would be beyond the scope of this chapter, we can say that the majority agrees on the need to offer to all citizens free medical care for serious diseases such as cancer. I sincerely hope that some changes will be implemented; in fact, there is no reason why end-stage kidney failure is a condition covered by the state, and cancer is not.

Physician empathy cannot be limited to a compassionate attitude. An essential element of physicians empathy is to comprehensively understand the diagnosis and the treatment possibilities. Rarely, if ever does a single possibility exist. The choice will be made after prudent consideration of all elements: the goal of the treatment (cure or palliation), efficacy and side effects, and the patient’s personal attitude toward each of the treatment possibilities, expected compliance, and familial support.

Oncologists treating patients in areas with limited health care resources should acknowledge that sometimes the best available agents are not the newest ones. When treating cancer, it is important to keep in mind the well-known phrase: “Treatment should not be worse than the disease”; we must include the alleviation of suffering.

Not all progress in cancer treatment is about very expensive drugs. A recent report on a randomized trial of early palliative care for patients with advanced lung cancer confirmed that palliative care will not only alleviate symptoms and improve quality of life but may also prolong survival. Of similar importance is rational indication for palliative radiotherapy.

In conclusion, while it might be true that oncologists treating patients in a limited-resource environment often feel frustration because of their inability to access more sophisticated and modern treatment, human relations go much deeper. Understanding how to communicate in such an environment helps not only patients dealing with cancer, but helps us become better people.

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