

Quality cancer care

Ten rights that should be guaranteed to every cancer patient

→ Elizabeth DeVita-Raeburn

If equal access to quality cancer care is to be more than an aspiration, we need to define minimum standards. ASCO and ESMO have now taken a lead with a consensus statement.

There are parts of Europe where newly diagnosed cancer patients are not given access to their diagnostic reports. They have to trek to their general practitioner to find out what the reports say. In other regions, it tends to be the patient's family that is told the diagnosis. They then decide what, if anything, to tell the patient. In many places, the notion of a second opinion is laughable. In some countries, patients diagnosed with cancer stand to lose their job; they're either summarily sacked or their working lives are made so difficult they are forced to quit. And, despite scientific advances that should produce good outcomes, cancer survival rates vary dramatically from country to country, because patients do not all have access to the same standards of care.

"The progress that's been made in the basic science of cancer and treatments for a variety of tumours faces tremendous obstacles in much of the world in terms of application," says Gabriel Hortobagyi, president of

the American Society of Clinical Oncology (ASCO), and Professor of Medicine and chairman of the Department of Breast Medical Oncology at the M.D. Anderson Cancer Center in Houston, Texas.

Many parts of the world, he says, have not even begun to think about the broader issues pertinent to the lives of those struggling with a cancer diagnosis – such as discrimination on the job, rehabilitative needs after treatment, and even problems with such basic tasks as getting a mortgage, because of the cultural misapprehension that a cancer diagnosis inevitably means a death sentence.

In response to the enormous challenges faced by cancer patients around the globe, ASCO and the European Society for Medical Oncology (ESMO), the two largest associations of clinical oncologists, recently issued a joint statement on quality cancer care (see p 48). Announced in June at ASCO's annual meeting in Atlanta, Georgia, it calls for, among other things, privacy, confidentiality and dignity for patients,

access to medical records, non-discrimination and the right to innovative treatment.

The decision to make it a joint statement was an easy one. "We felt it was critical for us as organisations that cover much of the Western world, and influence, to a large extent, what happens in the oncology world, to provide the road map about the principles on which we should base our clinical approach to cancer patients," says Hortobagyi. "It gives it more power and value," agrees Håkan Mellstedt, president of ESMO and Professor of Oncologic Biotherapy and managing director of the Department of Oncology at the Karolinska University Hospital in Stockholm, Sweden.

But agreeing on the principles that should be the standard of care is one thing; putting those standards into operation will be something else again. The statement, which is aimed largely at the national political machineries that control health-care systems, isn't enforceable by law. Neither society can force countries

and their oncologists to adopt it. “A statement,” agrees Hortobagyi, “does not mean implementation.”

“It’s easy to say everybody should have access to high-quality care, but if the infrastructure and resources don’t exist, it’s very hard to implement,” says Hortobagyi. “And it’s easy to say everyone should have access to preventive services, but if it’s not in the budget, it’s much more complicated. We hope, over the next several years, to cause gradual alterations and change, first in the cultural acceptance of these issues, and secondly in the rearrangement of resources to fully implement the plan,” he says.

Some critics say the statement is not as strong as it could have been, partly because of concerns that by raising the bar too high, developing countries with limited resources would be unable to meet the standards. But neither the ASCO nor the ESMO president felt the statement had been watered down.

“We are critically aware that, in many parts of the world, the limitation of resources will make this extremely difficult to implement fully,” says Hortobagyi, “but that’s no justification for setting the bar any lower.”

Mellstedt agrees. “I think it’s time for them to start to see whether it’s possible to reallocate money from other areas to address the priorities within their society. Clearly there are problems with the health-care system that need to be revised.”

Both societies have made a commitment to continue to work together to promote the right to quality care via an ASCO–ESMO Task Force. The statement was published in the July 20 issue of ASCO’s *Journal of Clinical Oncology*, and the July issue of ESMO’s *Annals of Oncology*, and is also available online at each organisation’s website.

ESMO has given staff in its Brussels office, and ESMO national representatives in each country, the task of distributing the statement among members of the European parliament, along with documentation showing the difference in survival rates between countries.

Heinz Ludwig, chairman of the ESMO Cancer Patient Working Group, says he hopes that ASCO and ESMO members – there are more than 30,000 in all – “will act as a multiplier of this idea, and use this statement in their interactions with their policy makers and society in general.”

Mellstedt adds that they are also counting heavily on the cooperation of patient advocacy groups, whom they see as critical to the cause. “We have to have all the patients on board. They are often the most effective at distributing the message. They are a very powerful pressure group. Previously,” he says, “we have forgotten the patients.”

ASCO expects to invest several million dollars in the coming years on, among other things, a task force on quality affairs to address issues of

quality measurements; an online quality assessment tool that physicians can use to evaluate their performance in the care of cancer patients; and a task force to push through initiatives related to issues of survivorship.

But both societies say it’s just a start. What the document really does, for now, is set a standard, much as both organisations once did by collaborating on a global core curriculum for medical oncologists. “It sets a bar where the application of certain principles should get to as a minimum,” says Hortobagyi. “It provides a goal to national organisations, and to patient survivor and advocacy movements. And it provides guidelines for individuals in politics who make decisions that influence quality of care.”

“And that will make it much easier to get into a discussion with those who need to provide improved quality of care, regardless of where they are, as to where they should be heading and put pressure on them to come in line. ESMO and ASCO have taken a very courageous first step,” he says. “We hope it’s contagious.”

But the proof will come in what actually happens on the ground, in hospitals, clinics and doctors’ offices. Five to ten years from now, for instance, will all cancer patients leave the hospital with a copy of their diagnostic report in their hand? Or will there still be some who have to persuade their GP to reveal what it says?

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ASCO-ESMO consensus statement on quality cancer care

The American Society of Clinical Oncology (ASCO) and the European Society for Medical Oncology (ESMO) are both dedicated to the provision of quality cancer care to patients worldwide. Recognising that resources, financial and otherwise, vary greatly from country to country and that systems for providing medical care are similarly varied, ASCO and ESMO nevertheless believe that health care plans should aspire to meet certain common goals to ensure access to, and continuity of, quality cancer care.

1 Access to Information. Patients should receive adequate information about their illness, possible interventions, and the known benefits and risks of specific treatment options. These matters should be discussed with qualified health care personnel who are committed to responding forthrightly to patient inquiries. Patients should have the ability to ascertain names, roles and qualifications of those who are treating them.

2 Privacy, Confidentiality and Dignity. Patients should have the benefit of privacy with respect to their diagnosis and treatment. Medical records and other patient-specific information, including genetic information, should be regarded as private, except to the extent that they are required to be shared for treatment or payment purposes. If access to patient-specific information is necessary for research efforts, including clinical trials, epidemiological research, translational research or other clinical investigations, patients should be given the opportunity to agree to such uses of their information for the benefit of cancer patients in general. Patients should be treated with dignity at all times.

3 Access to Medical Records. Patients should be permitted to review

their medical records and obtain copies for free or for a reasonable fee. Health care providers should be available to explain the contents of medical records to patients.

4 Prevention Services. Individuals should be advised with respect to prevention of cancer and provided any preventive interventions that are evidence-based and available.

5 Non-discrimination. Access to health services should be provided without discrimination as to race, religion, gender, national origin, or disability. Patients should also be free of discrimination on the basis of their disease with respect to both employment and health insurance.

6 Consent to Treatment and Choice. Patients should be empowered to participate in decision-making about their treatment and care to the degree they desire, and the health care team should respect those decisions. Patients should have access to a second opinion and the ability to choose among different treatments and providers.

7 Multidisciplinary Cancer Care. Optimal treatment of cancer should be provided by a team that includes, where appropriate, multidisciplinary

medical expertise composed of medical oncologists, surgical oncologists, radiation oncologists, and palliative care experts, as well as oncology nurses, and social workers. Patients should also have access to counseling for their psychosocial, nutritional and other needs.

8 Innovative Cancer Care. Patients should be offered the opportunity to participate in relevant clinical trials and should have access to innovative therapies, which may improve their disease outcome.

9 Survivorship Care Planning. Cancer survivors should be provided a comprehensive care summary and follow-up plan at the completion of primary therapy and systematically monitored for long-term and late effects of treatment. The need for rehabilitation services should be evaluated as part of the long-term follow-up plan.

10 Pain Management, Supportive and Palliative Care. Quality cancer care requires pain management, including the use of opioid analgesics, and other supportive care for conditions induced by cancer treatment or by the disease itself. When effective cancer therapy is no longer available, patients should have access to optimal palliative care and counseling.