Proposing a Bill of Rights for Patients With Cancer

Joseph O. Jacobson, MD, MSc; Leonard L. Berry, PhD, MBA; Patricia A. Spears; Karina Dahl Steffensen, MD, PhD; and Deanna J. Attai, MD

Oncologists naturally believe that the care they deliver is patient focused, a core part of their mission. Nevertheless, many patients with cancer perceive gaps in their care experience. They report such concerns as excessive waiting for appointments, for scheduled interventions to begin, and for return phone calls; a lack of coordination among their multiple clinicians; unclear answers about disease prognosis; and daunting financial challenges, frequently with little pertinent assistance. Physicians who are diagnosed with cancer themselves often evolve in how they view patient care. As oncologist Marc Garrick writes, "Until I became a patient [with cancer], the accumulated burdens of treatment...that can sap a patient’s will had escaped my imagination."

Patients with cancer have a right to their clinicians’ best efforts as healers and as caring human beings. They have a right to receive coordinated, timely care; to be listened to with compassion while receiving honest information; and to be guided with empathy through a dark place by a trusted expert partner. Research outside the medical field shows that the more important, personal, variable, and complex a service is, the more aware consumers become of clues related to that service. In health care settings, those clues include the modernity and comfort of the facility; the perceived coordination and efficiency of care delivery; and clinicians’ body language, words, and tone of voice. Cancer care is important, personal, variable, and complex in the extreme, putting patients and their families on high alert and deepening the need for clinicians to reassure and calm them.

We believe the time has come for the oncology community to articulate a bill of rights for patients with cancer that is intended to ensure equitable and high-quality care. It has been two decades since the Institute of Medicine (IOM) issued its seminal report, Ensuring Cancer Care. The scope was broad: It described the need to build reliable systems of care, to measure the quality of cancer care, and to coordinate research efforts. Anticipating the entire movement of patient-centered cancer care, the authors recognized the large divide between what patients with cancer experience and what their clinicians provide. The report made clear that all patients are entitled to understand their diagnosis, to have all treatment options described in an understandable manner, to have confidence that recommended treatment offers the “best chance of a good outcome consistent with personal preference,” and to have clinicians who respect them, listen to them, and advocate on their behalf.

In 2012, the IOM convened a second group of experts to determine whether the 1999 report had improved cancer care. The review yielded the publication of Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. As the title implies, the authors found many persistent—and some worsening—gaps in providing high-quality cancer care. They proposed a new cancer care framework that placed the patient squarely at the center of the care system.

Multiple patient bill of rights documents exist, but we could identify only one focused on cancer care. The European Cancer Concord (ECC), a partnership of European oncologists and patients, recognized disparities in public information about, and access to, cancer care—along with other issues in oncology care. The ECC developed the European Cancer Patient’s Bill of Rights, first issued in 2014 and updated in 2016. It focuses on the right of every European citizen to be proactively involved in their care, to receive accurate information and timely access to a diagnosis and subspecialty care, to be treated in a setting that ensures the best possible outcomes, and to receive affordable care. The European effort’s main thrust is to clarify and then mitigate disparities in cancer care across Europe. It proposes the 70:35 Vision: achieving 70% survival for all patients with cancer in Europe by 2035. It identifies barriers to success, highlighting wide variation in the availability of diagnostic and therapeutic services, access to expert care, timely evaluation, and treatment. In a proof of principle, the ECC reviewed the current state of lung cancer management across Europe. In great detail, the final report identifies major variations in access to specialized...
We think it is time for the oncology community to build on the European effort and articulate a cancer patient-centered bill of rights. We believe that the enumerated rights should match some of those identified by the ECC, but that they should focus less on broad policy and more on directly empowering clinicians to prioritize patients’ needs and wants as care is delivered. Our suggestion is guided by the IOM’s earlier publications with input from the patients with cancer, caregivers, and cancer clinicians with whom we have collectively worked for decades. Each of us is keenly aware of the difference between a well-prepared, well-navigated, and empowered patient with cancer and a less fortunate one—not just in the care experience, but often in outcome. We believe that every patient has the right to receive the best possible care that aims to achieve the best possible outcome.

Our 10 Principles for a Cancer Patient’s Bill of Rights (Table 1) intends to open a discussion, not be a fait accompli. It is a starting point for a much larger effort. Central to our thinking is that patients should understand their rights at the time of cancer diagnosis, that oncologists are in the best position to guide their patients, and that, from an advocacy perspective, ASCO is well positioned to advance a bill of rights. ASCO has supported innumerable patient-centered programs during its long history, partnering with patient advocacy groups and other professional societies. Supporting a bill of rights, guided by our modestly proposed principles, is a logical next step.

We acknowledge that oncologists alone cannot close the gap between the current state of cancer care and a more idealized one. Closing this gap will require sweeping changes in how our care is reimbursed and in how we manage our time. It will mean retraining physicians and staff to facilitate true team-based care, and it will demand raised expectations for all cancer clinicians, including how they coordinate care and close communication loops. The Center for Medicare and Medicaid Innovation has taken an important first step to change the paradigm. The Center for Medicare and Medicaid Innovation Oncology Care Model is a 5-year pilot project that incentivizes oncology practices to provide higher-quality, better-coordinated care through monthly management payments and the possibility for shared savings. Early data suggest that the Oncology Care Model has led to structural improvements in participating practices, reductions in hospitalization rates, and better management of end-of-life resources.

A cancer diagnosis may not be life ending, but it is often life changing and overwhelms most patients. It is likely to turn one’s life upside down, creating multiple, emotionally intense questions, such as: How do I tell my loved ones? Can I tolerate the effects of treatment? Can I continue to work? Will this bankrupt my family? How do I make the right treatment decision especially when I am offered options? Will I live? The entire oncology community must now speak up—and step up—for the rights of patients with cancer so that they, their families, and their clinicians can explore and answer these questions with dignity.

### Table 1. 10 Principles for a Cancer Patient’s Bill of Rights

<table>
<thead>
<tr>
<th>Principle</th>
<th>Patients have the right to</th>
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<td>Risk reduction</td>
<td>be educated about opportunities to reduce cancer risk, to be screened to detect cancer early, and to be appropriately counseled on the basis of the findings and the best available evidence.</td>
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<td>Diagnosis</td>
<td>have the right to timely access to trained subspecialists, to rapid diagnostic testing, and to accurate interpretations of their test results that are shared with all relevant clinicians.</td>
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<td>Multidisciplinary expertise</td>
<td>have the right to treatment planning may benefit from multidisciplinary discussion have the right to receive such a service.</td>
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<td>Treatment</td>
<td>have the right to balanced information about treatment options, provided in understandable language, that takes into account their priorities and values. Patients have the right to all of their questions answered, including candid and ongoing assessment of their prognosis. Patients have the right to receive up-to-date information about, and have access to, relevant clinical trials.</td>
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<td>Second opinion</td>
<td>have the right to seek a second opinion at any time in their cancer course.</td>
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<td>Coordinated care</td>
<td>have the right to have all testing and treatments provided in a timely and coordinated manner.</td>
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<td>Communication</td>
<td>have the right to read communications among the people who provide their care.</td>
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<td>Supportive and ancillary services</td>
<td>have the right to supportive and ancillary services that address cancer-related health issues (emotional sequelae, pain, symptoms, adverse effects) and personal issues (financial management, caregiving support). Patients have the right to counseling and other services to help them transition from active treatment to follow-up care.</td>
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<td>Privacy</td>
<td>have the right to expect that their privacy will be safeguarded by all members of the treatment team and by ancillary staff.</td>
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<td>Follow-up care</td>
<td>have the right to receive a treatment summary at the end of therapy that explicitly describes how their cancer will be observed, what signs or symptoms to look for, and whom to contact as needs arise.</td>
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REFERENCES
AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Leonard L. Berry
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Consulting or Advisory Role: Pfizer

Karina Dahl Steffensen
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Consulting or Advisory Role: AbbVie
Research Funding: AstraZeneca (Inst)

Deanna J. Attai
Open Payments Link: https://openpaymentsdata.cms.gov/search/all-entities?name=Deanna%20Attai

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