

Cancer Care at the Beginning of the COVID-19 Pandemic

Effects on Patients and Early Interventions to Mitigate Stresses on Care

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Purpose: A multidisciplinary panel of experts convened to review the early effects of the COVID-19 pandemic on cancer care in the United States as part of a symposium convened by the National Cancer Policy Forum in July 2021. **Methods:** Representatives from the cancer care community, patients, infection prevention, and a government agency provided insight into key elements of the response to and impact of the COVID-19 pandemic on cancer care in the United States in 2020.

Results: Multiple stakeholders worked quickly to adapt to provide seamless care to cancer patients with considerable success despite the profound uncertainties that faced us in the early days of the pandemic.

Discussion: The experiences of the early days of COVID-19 in the cancer community led to key recommendations toward the goal of preparing for the next major disruption to cancer care. These include increasing competency in emergent technologies, rapid communication, engagement of all key stakeholders in policy decisions, ensuring emergency preparedness, and advocating for permanent regulatory changes to minimize barriers to enable a unified cancer community to provide effective and readily accessible cancer care.

Key Words: Cancer, COVID-19, pandemic

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The arrival of COVID-19 in the United States in early 2020 led to rapid and significant disruptions in cancer care as the medical community raced to understand what was happening and how to respond to a new pathogen posing a special threat to the very patients we treat—older, immunosuppressed, and requiring ongoing medical care, as well as to the staff caring for these patients.

US health care is a decentralized and somewhat fragmented system and thus not well suited to respond to a disruptor such as COVID-19. Hospitals generally act independently, as do the providers who practice within them. Patients are insured through many independent private payors who devise their own parameters for coverage and/or through several government plans. Physicians are licensed by states and are only able to provide care within the states where they are licensed. Professional organizations such as the American Society of Clinical Oncology, the Commission on Cancer (CoC), and many others traditionally act independently.

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No cancer professional had ever experienced a situation like the COVID-19 pandemic, and therefore no one had experience in how to respond to it. In addition, the pandemic's rapid evolution, particularly in "hot spots" such as New York City, allowed no time for delay. In those first weeks and months, the oncology community (patients, families, and health care workers) responded rapidly in a variety of ways that are summarized here. The response across the many stakeholders was truly remarkable. In addition, government and private payors adjusted their coverage policies overnight and, among other actions, included parity coverage for telemedicine. States developed mechanisms to allow cross-state temporary licensure. The themes that characterized these responses included flexibility, collaboration, innovation, evidence-driven, safety, and dynamic.

ACADEMIC MEDICAL CENTERS

Most cancer research and much cancer care in the United States is carried out in academic medical centers, and the impact of the COVID-19 pandemic on cancer care in that setting was significant. One such center is the Sidney Kimmel Cancer Center in Philadelphia, which provides care at multiple sites across a large, 16-hospital system distributed between 2 states (Jefferson Health). The catchment area population served is dense, diverse, and associated with cancer incidence and cancer mortality rates exceeding the national average. Moreover, the health system took on a disproportionate burden of care for COVID-19 patients in the region; during each of the first 2 peaks of the pandemic, there were more than 650 COVID-19–positive inpatients on any given day in the system. Given the strain on the overall health system, the challenge of ensuring continuity in cancer care was formidable.

Despite the challenges, the Sidney Kimmel Cancer Center leadership identified key strategies that facilitated not only continuity but also safe expansion of cancer care during the pandemic. First, early development of rapid communication channels allowed for nimble, evidence-based decision making. For example, implementation of a daily, cancer-specific incident command meeting—which included representation from infectious disease experts—allowed rapid adjustment of guidelines to new evidence, resulting in effective operational execution of safe cancer care across all sites. Through this mechanism, and working in concert with Jefferson Health, cancer leadership declared surgical procedures (for cancer care or to rule out cancer) to be "essential" throughout the course of the pandemic. The team also declared clinical trials with curative intent to be essential, thus allowing for continuation of and/or opening of new clinical studies important for cancer care. Second, alignment with community practices in need of strategies to prevent care disruption provided significant benefit. Preexisting affiliations with smaller community practices that faced COVID-19–related challenges (e.g., personal protective equipment and/or staff shortages) allowed one of the Jefferson Health sites to offer care for patients in need. Third, pre-COVID adoption of technology allowed for rapid escalation of telehealth. Notably, prior to the pandemic, all Jefferson providers (including but not limited to cancer care)

regularly conducted telehealth visits. Thus, cancer providers were well prepared for the substantial increase in usage during the pandemic. This was, of course, not the case for many other academic centers who raced to bring telehealth capability online in a very short time.

COMMUNITY ONCOLOGY IN COVID RESPONSE

Community hospitals and practices are important public health hubs that serve local and regional populations, as are local physicians who provide inpatient and outpatient care. It is estimated that more than 60% of cancer patients in the United States are cared for primarily at community hospitals or community-based practices. Approximately 9% of cancer patients are hospitalized while on chemotherapy cancer treatment, highlighting the importance of having hospital bed availability in communities where patients live.¹ The pandemic posed 2 immediate dangers to hospital bed access: having sufficient bed capacity for cancer patients experiencing disease or treatment-related complications and keeping fragile cancer patients separate from active COVID-19 care in hospitals.

As an example of new models of collaboration in the face of the COVID-19 crisis, in Lancaster, PA, 3 medical oncology practices (“the practices”), historically competitors who utilize the same community hospital, joined in strategy planning to minimize cancer care disruptions. The practices explored local and global resource constraints, medical ethics, and care and safety of their staff in a rapidly changing medical delivery environment with very little established precedent or standardization.

To execute on this plan, the practices established a “Community Oncology COVID-19 Collaborative,” which comprised physician, nursing, and administrative leadership from each practice. The collaborative met by telephone for 30 minutes once weekly to review breaking lay news reports, medical literature, and published guidelines and to share experiences and solutions from within the practices. Participants set agendas and recorded and distributed minutes to maximize the value of their time together. COVID-19 screening, staff safety, modified patient care guidelines and expectations, and community, institutional, and Centers for Disease Control and Prevention guidelines were key considerations.

The practices addressed 3 top public health priorities: preserving hospital capacity, creating physician backup coverage for those who might fall ill, and creating community standards to continue providing lifesaving curative cancer care, as well as compassionate care for patients and families facing late-stage cancer.

The collaborative debated, agreed upon, and adopted shared approaches to safe practices and staff management. Each week practices updated what was working and what was not, creating an informal PDCA (plan-do-check-act) quality improvement cycle. Physicians from the largest practice provided hospital rounds coverage for the smaller practices, protecting those physicians from extra risk of exposure.

The largest practice developed and shared protocols to care for and protect vulnerable populations including those living in nursing homes, prisons, and other congregate living situations. Protocols were shared with facility medical directors, patients, and families and regularly modified based on their input and changing circumstances.

Medical providers face significant moral distress when resource constraints impact usual standards of care and individual rights and preferences. One practice met such ethical challenges with open discussion, information sharing, and a framework for allocation and protection of staff, resources, and supplies. The COVID-19 impact on cancer treatment delivery was addressed through a 3-times-weekly cancer treatment conference built on the classic tumor board model, adding in COVID considerations to usual discussions of cancer diag-

nosis, stage, comorbidities, and patient values. Each cancer case presentation was followed by a group consultation that recommended 1 of 3 options: continue standard therapy, modify therapy, or discontinue therapy temporarily or permanently. This COVID-19 case discussion conference was well received by physicians, care teams, patients, and families and led to therapy changes in approximately 10% of cases.

Much was learned by the participants from these collaborative adaptations. The Community Oncology COVID-19 Collaborative continues with twice-monthly meetings and is now addressing vaccine and virus variant issues. The COVID-19 case discussion conference also continues as a once-weekly palliative oncology case conference, demonstrating the adoption of lessons learned from COVID-19 to ongoing practice. Transitioning competitive practices to a collaborative community that persists is a bright spot in a dark time.

RESPONSE OF ORGANIZED CANCER PROGRAMS AND SOCIETIES TO THE COVID-19 PANDEMIC

Despite watching the pandemic unfold in China and then in Europe, US cancer programs had little idea what to expect or how to provide safe and effective care for their cancer patients. While cancer does not “pause” for pandemics, prioritization schema helped programs to optimize care where possible.

Professional organizations such as American Society of Clinical Oncology, CoC, and many others came together virtually and developed guidance on optimizing cancer care during the pandemic within weeks. As an example, the CoC, The National Accreditation Program for Breast Centers, the American Society for Breast Surgery, the American College of Radiology, and the National Comprehensive Cancer Network published a detailed article on how best to treat breast cancer patients in the context of the pandemic and resource constraints in early April 2020, just weeks after COVID-19 arrived in the United States. The 30 cancer centers that constitute the NCCN met weekly to share experiences and strategize on approaches to provide cancer care safely and effectively, disseminating guidance through their networks and through published articles. When COVID-19 vaccines became available for patients, the NCCN formed a COVID-19 Vaccination Task Force with broad stakeholder representation and in 11 days produced and posted guidelines for vaccinating cancer patients that were updated as more information became available.

Many groups, including the NCCN and the breast cancer consortium noted above, developed and produced webinars within days, often attracting nearly 1000 active participants and countless more who viewed the posted recordings. This is a clear indication of the cancer professionals' acute need for guidance in what was an unprecedented time.

What is remarkable was the degree of frictionless collaboration and speed with which this all took place. Rivalries and discord were put aside, and all pulled in the same direction. It is hoped that, out of this terrible pandemic, a renewed sense of community will come among cancer professionals and their organizations, as well as among the payors and regulators.

THE VITAL COLLABORATION BETWEEN SPECIALISTS IN CANCER AND INFECTIOUS DISEASES

The early weeks of the COVID-19 pandemic confirmed the importance of and accelerated the longstanding and vital collaboration between cancer care and infectious disease teams. The relationship has traditionally been a close one because of the importance of infection prevention (IP) and treatment in the large population of immunosuppressed cancer patients, especially those with

hematological malignancies or those receiving stem cell transplant or cellular therapies. This led to prioritization of transplants and cellular therapy to those at highest risk of cancer progression in the earliest weeks in many centers with subsequent reversion to the norm as hospital capacity stabilized. Infection prevention teams were also at the forefront of organizing symptom screening of patients and staff to minimize the possibility of COVID-19 transmission in these highly specialized medical facilities, while still allowing for care of COVID-19-infected patients. Infection prevention teams deployed rapid testing facilities often in unused conference rooms or drive-by facilities and took advantage of statistical modeling to plan for hospital, operating room, and intensive care unit capacity and need for personal protective equipment. As COVID-19 vaccines came into practice, IP experts frequently worked with state and local governmental agencies to oversee an equitable strategy for administration, based on ever evolving scientific evidence. Their role will continue as we deploy more COVID-19 therapeutics such as preventive or therapeutic antibody cocktails and small molecule antivirals. An important outcome from the IP perspective is to “save our notes” about what worked and what did not work so that we will be better prepared for the next pandemic; such an approach has already helped us to deal with subsequent waves of COVID-19 cases and variants.

THE CRITICAL ROLE OF GOVERNMENTAL AGENCIES

The Centers for Medicare & Medicaid Services (CMS) established a number of significant regulatory flexibilities early in the public health emergency in March 2020 and expanded them over time, with the goal of allowing health care providers to focus on keeping their patients under care and safe during the public health emergency.² These flexibilities included telehealth, where Medicare greatly expanded the ability for patients to be seen virtually to limit their potential COVID-19 exposures, which is critical for cancer patients who are immunocompromised. Stakeholders have repeatedly described the benefits of telehealth waivers, including for cancer care, to facilitate health care providers' ability to better manage their patients' care without requiring the patients to come into the office during the pandemic.

Another area where CMS provided regulatory flexibilities that evolved during 2020 was related to what constitutes hospital care. Initially, CMS announced the Hospitals Without Walls program, which allowed hospitals to provide services in locations that normally would not be permitted by CMS to provide hospital-level services.³ Then, in November 2020, as hospitals anticipated that their capacity would be strained, CMS announced that hospitals could request waivers to give additional flexibility to treat eligible patients in their homes, including a relaxation of the requirement for provision of 24/7 onsite nursing services for certain less acute patients.⁴ Experience with the Acute Hospital Care at Home program may provide valuable insights for cancer care given recent interest in incorporating hospital at home flexibilities in oncology alternative payment models.⁵

In addition to the general Medicare flexibilities, the CMS Innovation Center established some flexibilities for its alternative payment models in June 2020.⁶ Generally, these flexibilities focused on payment, reporting requirements, and model timing. Several guiding principles informed which flexibilities were permitted, including that the CMS Innovation Center wished to continue its commitment to value-based care and payment while also minimizing risk and reduce burden so model participants could focus on patient care. For the ongoing Oncology Care Model (OCM), the CMS Innovation Center offered the following:

- (1) Participants could opt out of risk, and participants staying in risk would have episodes for patients diagnosed with COVID-19 removed from their payment reconciliation.
- (2) Reporting of certain quality, clinical, and other data was made optional.
- (3) The voluntary model was extended for 1 year.

These changes were informed by feedback from oncology practices participating in OCM. For example, for the first flexibility, oncology practices described significant challenges in managing cancer patients where adverse effects from their chemotherapy included fever that may resemble infection with COVID-19. Further, in addition to precipitous drops in patient volumes early in the pandemic, treatment patterns changed, such as delay of surgery for certain early-stage breast cancer patients in favor of preoperative endocrine therapy. These types of variations could lead to unprecedented cost patterns that could vary regionally and make benchmarking difficult and risky, both for Medicare and OCM practices. For the second flexibility, some oncology practices had to divert staff, who would normally report data to CMS, to other roles. Finally, for the third flexibility, there was concern that ending OCM and potentially starting a new alternative payment model in oncology could distract oncologists from patient care.

The CMS Innovation Center also learned that OCM helped oncology practices develop quality improvement habits that were critical in responding quickly and nimbly to the COVID-19 pandemic. More broadly, stakeholders commented on the importance of value-based payment approaches in providing revenue stability with unexpected changes in patient and service volume. Looking ahead and considering potential long-term implications of COVID-19 on cancer care, the CMS Innovation Center and others are considering how delayed cancer screenings⁷ may impact cancer care and outcomes going forward, which—if any—of the changed treatment patterns during the pandemic may become permanent, and whether some of the flexibilities around telehealth, hospital at home, and others should be continued. These are just some of critical questions that will inform how high-value, person-centered cancer care is delivered in a future post-COVID-19 world.

THE CRITICAL IMPORTANCE OF THE PATIENT PERSPECTIVE

Thanks to some of the rapid adjustments in medical practice and regulation outlined above, patients generally continued to receive needed care for active malignancy throughout the first year of the pandemic. Indeed, the Annual State of Cancer Survivorship Study undertaken by the National Coalition for Cancer Survivorship in June 2021 showed that most patients surveyed felt that their care was the same or better (90%) during the pandemic. Approximately 40% of those who had appointments during the first year of COVID-19 used telehealth services, and most respondents rated the telehealth appointments as excellent or very good. Based on their experiences, respondents to the survey felt that in-person appointments are preferred for most encounters for oncology care, although telehealth was felt to be an excellent alternative for counseling and education, medication management, sharing test results, and survivorship care. These views should play a critical role in the design of cancer care delivery models going forward. Initial fears about exposure to COVID-19 decreased significantly with the advent of the COVID-19 vaccines in late 2020, and many cancer patients were early vaccine recipients. However, among cancer patients who had not received a vaccine as of the survey date, 46% said they were unlikely to receive a vaccine, citing trust as the biggest factor in their decision.

COVID-19 EXPOSES STRUCTURAL PROBLEMS THAT DRIVE HEALTH DISPARITIES

As scientists scrambled in the early months of 2020 to understand why COVID-19 was taking a greater toll on racial and ethnic minorities than Whites, initial attention focused on biological differences. For example, it was hypothesized that genetic polymorphisms could contribute to these disparities.⁸ Ultimately, it was demonstrated that neither genetic nor immune predisposition nor biological associations of race and ethnicity seemed to explain COVID-19 death. Instead, it was education, medical insurance status, and income that held true predictive value.⁹ Throughout the pandemic, it has become clear that the social determinants of health that exist now cannot be separated from the history and policies that created these circumstances.

In 1899, Du Bois¹⁰ identified structural disadvantages that Black Americans face, including crime, poverty, and illiteracy. Starting in the 1930s, the practice of redlining prevented Black families from buying houses in “desirable” neighborhoods.¹¹ Then, with the creation of the national interstate system in the 1950s, highways were built right through these majority-Black neighborhoods,¹² destroying thriving communities and exposing residents to risk factors for comorbid disease. Decades of social and geographic disadvantage ultimately led to more cases of COVID-19 and poorer outcomes.

These same structural factors contribute to cancer disparities as well,^{13,14} and, if there is one positive outcome from the COVID-19 pandemic, hopefully it is increased and universal awareness that structure matters.

Another lesson of the pandemic is that there is a limit to how much medical miracles can accomplish. We witnessed a true miracle when extremely effective COVID-19 vaccines were produced in a fraction of the time that vaccine development has ever taken before. Yet, we see widespread hesitance and outright refusal of these vaccines by some, which allowed variants to emerge and cases to surge. At this writing, our intensive care units are once again overrun, predominantly with unvaccinated COVID-19 patients who did not trust the medical establishment. Despite our miracles, we fell short of building the trust necessary to stop the pandemic with medicine alone.

To inspire widespread uptake of lifesaving medical advances, we need more effective communication between our academic and government institutions and the people. And it must be genuine 2-way conversation. According to the adage often attributed to Theodore Roosevelt, “Nobody cares how much you know until they know how much you care.”

As an example of how trust-building can happen, VCU Massey Cancer Center in Richmond partnered with local faith leaders to bring facts to the community every single Friday beginning in March 2020 because there was trust in faith leaders when there was no trust in doctors and scientists. Through this collaboration, churches hosted vaccination events and encouraged their congregants to practice masking and social distancing. By choosing not to have regular services during periods of high community transmission, these pastors probably saved thousands of lives.

By working closely with the communities they serve, cancer centers can combat not only the biology of disease but also structural issues, including lack of trust and lack of access, to keep people stay safe and healthy.

SUMMARY

The COVID-19 pandemic has tested the world in general and cancer patients and care providers in particular in ways that no one

had previously experienced, and these challenges continue. Multiple stakeholders worked quickly to adapt and adopt new strategies to provide seamless care to cancer patients with considerable success in the face of the profound uncertainties that confronted us in the early days of the pandemic. From the experiences of the early days of COVID-19 in the cancer community come 6 recommendations toward the goal of preparing for the next major disruption to cancer care: (1) prepare oncology teams by supporting competency in emergent technologies; (2) enrich use of rapid communication platforms for care teams across geographies; (3) include key stakeholders in cancer policy decisions; (4) develop emergency plans with community stakeholders, (5) advocate for permanent regulatory changes to minimize the barriers to enable effective cancer care based on these experiences, and (6) unite as a single cancer community with a single vision and purpose centered around the well-being of our cancer patients.

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