Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.
The Coronavirus Disease 2019 (COVID-19) Pandemic: A Patient-Centered Model of Systemic Shock and Cancer Care Adherence

Ruth C. Carlos, MD, MS, Kathryn P. Lowry, MD, Gelareh Sadigh, MD

Systemic stressors, such as the 9/11 attack or the 2008 to 2009 financial crisis, result in multidimensional changes at multiple levels that influence health, survival, and health-related quality of life. Coronavirus disease 2019 (COVID-19) represents an unfortunate “natural experiment” in which the effects of these external stressors on patient outcomes can be assessed. First, COVID-19 created an economic crisis, with at least 36 million Americans filing for unemployment [1]. Fewer jobs result in less income and loss of insurance coverage, exacerbating health-related financial hardship especially in cancer patients. Second, the threat of COVID-19 is stressful among cancer patients and older individuals, who are at elevated risk for infection and poorer outcomes. Third, during the pandemic, people curtailed outside activities, and care institutions reduced nonurgent service availability. The World Health Organization previously outlined a multi-dimensional framework of adherence [2], which can be adapted for understanding care utilization during the current pandemic (Fig. 1). This model accounts for the patient-level factors and health system factors that independently influence care utilization, leading to patient-initiated or provider-initiated care delay or nonadherence. We adapted a model developed by Yabroff et al [3] that additionally integrates COVID-19-related changes at the national, state, or local levels interacting with patient-level and system-level characteristics to heighten or mitigate the risk of distress and financial hardship (Fig. 2).

Omnipresent media attention, shelter-at-home orders resulting in social isolation, state and local leadership distrust, and local COVID-19 infection rates induce distress in multiple domains (eg, anxiety, depression, or loneliness and can result in inappropriate coping behavior such as increased smoking or alcohol use). In addition, the emotional and financial distress from COVID-19 may result in care nonadherence as a maladaptive coping response [3].

COVID-19–RELATED CARE DELAY AND POTENTIAL DISEASE STAGE SHIFT

During the acute phase of the pandemic, health systems closed outpatient centers, delayed nonurgent care, and focused efforts on managing those with COVID-19, leading to predominately provider-initiated care delays [4]. However, patients wary of COVID-19 have also self-restricted seeking medical attention even when necessary [5]. The net result has been a dramatic reduction in outpatient care volumes, which were reduced by 60% overall in April 2020 and remained 31% lower in May 2020 [6]. The impact on cancer screening services has been particularly profound: a recent white paper released by the Epic Health Research Network reported March 2020 utilization of breast, colon, and cervical cancer screening had declined by 94%, 86%, and 94%, respectively compared to average volumes from 2017-2020 [7]. Office visits with specialty providers has also declined. Oncology provider visits were nearly half between the first week of March and the first week of April 2020 and rebounded to only 74% of normal volumes by early May [6]. The full impact of these declines and delays in care is not yet known but is worrisome, as time to diagnosis and treatment initiation is known to predict worse disease and poorer cancer outcomes [8].

Cancer care encompasses cancer prevention and control behaviors, which may be sensitive to COVID-19 related distress or financial distress. For example, when multiple forms of screening exist, price sensitivity may steer patients preferentially to one screening test or another, either due to COVID-19-related insurance change or income loss. Specific to breast screening, as a US Prevention Service Task Force Grade B service, digital mammography is fully covered by all nongrandfathered plans (approximately...
98% of the insurance market) under the Affordable Care Act; however, tomosynthesis may require a copayment determined by insurance benefits. Cost-based preference for digital mammography may result in false-positives that could have been avoided by tomosynthesis.

As we transition into the recovery phase, we slowly reschedule delayed imaging cases, including cancer screening and surveillance, using expert guidelines to ensure that patients remain safe [9]. However, services delays will likely continue as radiology practices accommodate pent-up demand of previously delayed imaging, cope with current imaging needs, and decrease throughput to ensure appropriate distancing and disinfection measures.

Patient-initiated nonadherence is also projected to persist even after reopening [10]. The economic toll of the pandemic will certainly constrain many patients’ financial resources and ability to afford out-of-pocket expenses of health care visits, including imaging. We hypothesize multiple factors beyond price sensitivity and cost of care influence continued patient-initiated care nonadherence for recommended routine and urgent care. Some patients may struggle with mistrust of information about the risks of infection and effectiveness of prevention measures because of inconsistent messaging between experts, local and national leadership. Leaders at all levels must address these concerns responsibly and safely. Otherwise, continued patient-initiated delays in seeking care may result in greater disease severity, complications, more difficult treatment after diagnosis and poorer outcomes.

DISPARITIES IN CARE NONADHERENCE
As data continue to emerge, a disproportionate burden of infections, adverse outcomes, and deaths are borne by African Americans and Hispanics, particularly at the epicenter of the pandemic [11], providing an uncomfortable update on persistent disparities. Many of us are privileged to work from home even as essential workers, have reasonable sick leave policies, or have enough resources to accept a furlough. We are Internet-enabled with fast speeds that allow binge-watching our favorite mind candy or Zooming (Zoom, Vancouver, Washington) with friends and coworkers to maintain social contact and connection. Social determinants of health, which are broader determinants of wellness beyond race or income, include living situations (eg, high-density housing), access to care (eg, functional reliable public transit), and community (eg, socioeconomic status of the neighborhood), have assumed a greater prominence, and indicate additional populations with higher risks of COVID-19-related emotional and financial distress. Those who work or live where safe distancing is not possible or have 0-hour contracts with no guarantees of minimum work hours or sick leave may be more susceptible to emotional or financial distress and are more likely to forgo preventive or diagnostic care.

MODERATORS OF HEALTH BEHAVIOR AND CARE UTILIZATION
Both conceptual models presented in this article indicate that psychosocial distress and financial distress have the potential to influence care nonadherence. Depression and social well-being (including loneliness and social connection) increase the probability of early discontinuation of endocrine therapy [12]. Insurance type [13] and insurance loss [14] even in the era of the Affordable Care Act result in decreased care access and increased care nonadherence.

Cancer patients are at increased risk for financial hardship because of high out-of-pocket medical expenses and lost income caused by cancer and treatment. Financial hardship includes...
three main domains of material conditions (eg, medical debt), psychological responses (eg, financial worry), and coping behaviors (eg, care non-adherence) and is linked to worse health-related quality of life and survival. High out-of-pocket expenses lead to change, delay, or non-utilization of care including medication in 12%-75% of patients [15,16]. For patients in this vulnerable population, COVID-19-related financial hardship can exacerbate existing financial risk.

**PROMOTING RESILIENCE**

Perceived self-efficacy, belief that one can perform difficult tasks to obtain desired outcomes, confers a sense of control to modify stressful environments [17] that can translate into resilience during COVID-19-related distress and financial hardship risks. Self-efficacy plays a moderating role in the relationship between depression and distress in cancer patients. Financial self-efficacy (ie, confidence in managing money) independently predicts financial hardship among cancer patients and their caregivers and among multiple sclerosis patients [18]. We posit that high general or financial self-efficacy predicts improved well-being [17] and lower prevalence of care nonadherence, promoting resilience during a systemic stressor that mitigates its deleterious effects. Institutional practices can also be structured to support patient self-efficacy.

**SUMMARY**

COVID-19, like other pandemics and systemic shocks, affected the whole of society and led to a near-complete halt of economic activity and care provision focused on the most acute cases. Even after entering the recovery period, there remains a possibility of intermittent outbreaks. Information dissemination during the acute phase of the pandemic seemed to have been driven by ideology, half-truths and mistruths, leading to mistrust of institutions traditionally thought to be a public good. Further, perceptions of lack of protection from their employers and the literal risk of life to provide essential services, both within and outside the healthcare enterprise has further eroded belief in the system. Patients must make decisions to continue to engage in preventive, diagnostic, and therapeutic care, under conditions of uncertainty, possible mistrust, and infection fear. The economic consequences further challenge patients to afford care, even if they choose to participate. Civic leaders at all levels and healthcare systems, physicians and other providers must regain trust that will promote appropriate care utilization. In the prevention and management of cancer, the most worrisome consequence of care delay or nonadherence is later stage diagnosis or stage shift. The conceptual models provide a framework for future analyses of the ongoing consequences of COVID-19.
REFERENCES

Ruth C. Carlos, MD, MS, is from the University of Michigan, Rogel Cancer Center, Ann Arbor, Michigan. Kathryn P. Lowry, MD, is from the University of Washington, Seattle Cancer Care Alliance, Seattle, Washington. Gelareh Sadigh, MD, is from Emory University School of Medicine, Atlanta Georgia. 
Dr Lowry reports grants from GE Healthcare, outside the submitted work. Dr Sadigh reports grants from General Electric—Association of University Radiologists Radiology Research Academic Fellowship (GERRAF), during the conduct of the study. Dr Carlos reports salary support from JACR, during the conduct of the study. Dr Lowry is employed by the University of Washington. Dr Sadigh is employed by Emory University. Dr Carlos is editor-in-chief of the JACR.

Ruth C. Carlos, MD, MS: University of Michigan, 1500 E Medical Center Dr, Ann Arbor, MI 48109; e-mail: rcarlos@med.umich