

Chapter 9: Navigating the Continuum of Care: Common Goods and Uncommon Experiences

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In light of his experience as clinical bioethicist in a healthcare institution in the U.S.A. (Anne Arundel Medical Center in Annapolis, MD), Christian Cintron reflects on concrete challenges—from the COVID-19 pandemic to the increasing costs of cancer care for individuals and families—that test the ability of providing care to cancer patients. Hence, policy reforms are urgent. They should aim at transforming practices in prevention and in providing care, while avoiding what he calls “financial toxicity.” The stories of three patients exemplify both the ethical concerns and the needed structural solutions to foster prevention. The equitable participation of cancer patients through solidaristic practices exemplifies one approach leading to systemic improvements.

In late 2020, as the United States experienced a pre-holiday season lull in COVID-19 cases, a team of medical oncologists practicing in New York expressed their concerns for cancer patients whose care had been and would continue to be disrupted by COVID-19.¹ They argued that their patients, predominantly racial and ethnic minorities, were more likely to have jobs as essential workers that increased their risk of COVID-19, to work lower income jobs with minimal or no health insurance, to experience fractured care related to the various technological requirements and personal desire for effective telemedicine and transportation resources, and to demonstrate inadequate levels of health care literacy. These concerns were largely validated by a COVID-19 and cancer outcomes study that reported a decrease in all visits by Hispanic cancer patients when

¹ See Onyinye D. Balogun, Vivian J. Bea, and Erica Phillips, “Disparities in Cancer Outcomes Due to COVID-19: A Tale of 2 Cities,” *JAMA Oncology* 6, no. 10 (2020): 1531–1532.

compared to White patients, and that both Black and Hispanic patients were less likely to use telehealth during the pandemic.² Both the results from the study and the warnings from Drs. Balogun, Bea, and Phillips highlight some of the everyday challenges in the provision of comprehensive cancer care. Without categorizing their concerns, the oncologists identify exemplary ways in which health care is influenced by the social determinants of health that effectuated an inequitable distribution of health for persons who suffer from those social factors disproportionately. In addition to the educational, socioeconomic, and transportation factors noted by the oncologists, other social, health system, and economic factors influence health. The interrelated dimensions of health and health care affect people's participation in health care, their ability to contribute to family and communal needs, and ultimately their promotion of the common good. Cancer care, particularly for the marginalized populations about which the COVID-19-worried oncologists were concerned, is an important context for examining the conditions necessary for health that are not only related to the cause of disease but also to its remediation.

The common cancer care protocol of surgery, chemotherapy, and radiation has been relatively unchanged in recent decades.³ Though personalized for each individual, the efficacy of the protocol is influenced by genetic and biologic variations, as well as influential social variations that contribute to or inhibit the remediation of cancer. Common among the social influences leading to personalized adjustments in plans of care are the short and long-term financial consequences of cancer care. Much

² See Andrew L. Schmidt, Ziad Bakouny, Sheena Bhalla, John A. Steinharter, Douglas A. Tremblay, Mark M. Awad, Alaina J. Kessler, Robert I. Haddad, Michelle Evans, Fiona Busser, Michael Wotman, Catherine R. Curran, Brittney S. Zimmerman, Gabrielle Bouchard, Tomi Jun, Pier V. Nuzzo, Qian Qin, Laure Hirsch, Jonathan Feld, Kaitlin M. Kelleher, Danielle Seidman, Hsin-Hui Huang, Heather M. Anderson-Keightly, Sarah Abou Alaiwi, Talia D. Rosenbloom, Penina S. Stewart, Matthew D. Galsky, Toni K. Choueiri, and Deborah B. Doroshow, "Cancer Care Disparities During the COVID-19 Pandemic: COVID-19 and Cancer Outcomes Study," *Cancer Cell* 38, no. 6 (2020): 769–770.

³ See Azra Raza, *The First Cell: And the Human Costs of Pursuing Cancer to the Last* (New York: Basic Books, 2019).

attention has been paid to alleviating the financial burden experienced by patients, their families and, by extension, society over the last decade, but the challenges created by the totality of costs remain. Because of the ways in which cancer care is influenced by the social determinants of health,⁴ attention to the costs and the manner they disproportionately affect some groups helps illuminate the interdependent nature of the social determinants of health within the experiences of cancer care. Not being able to maintain participation in care because one cannot afford co-pays, utility bills, adequate housing, or quality food, among other financial responsibilities, reminds us that there are innumerable, interrelated, socially-mediated obstacles to overcome as we look to create the necessary conditions for all persons to participate equitably in cancer care.

The Social Determinants of Health

The influence of the social determinants of health, and in particular the crosscutting determinant of socioeconomic status, is known to disproportionately affect the delivery of health care to racial and ethnic minorities. In cancer care, the effects of lower socioeconomic status upon racial and ethnic minorities are amplified because of the high costs of cancer care generally and, more specifically, because of the exceptionally high costs relative to the timing of diagnosis, the type of cancer, and treatment. While the challenges emanating from the social determinants of health are widely known, the societal acceptance of those challenges is most alarming. Failure to address the root causes responsible for the disparate experiences in cancer care demonstrates a lack of commitment to establishing and maintaining the conditions necessary for individuals to pursue their own health and well-being. In so doing, the collective malaise undermines not only the potential for the health of Navigating the Continuum of Care: Common Goods and Uncommon Experiences marginalized patients but also the totality of the health care system as cancer care costs go unfettered and the deleterious financial consequences distress families and healthcare institutions.

⁴ See Schmidt et al., “Cancer Care Disparities During the COVID-19 Pandemic.”

The systemic effects of the social determinants that undermine or inhibit the health of certain individuals demonstrate myriad challenges to achieving the common good, understood as “the sum of those conditions of social life which allow social groups and their individual members relatively thorough and ready access to their own fulfillment” (*Gaudium et Spes*, no. 26). While appeals to the common good may not resonate with the responsible institutions and the persons comprising them (as evidenced by the lack of change in the face of known disparities and their causes), it is more likely that exploring the particular ways in which the lives individual cancer patients are affected by the costs and interrelated social determinants of health will inspire much-needed change. Several inpatient vignettes will highlight the ways in which the current approach to the provision of cancer care and its related costs limit the ability for individuals and society writ large to achieve the common good.

Three Patients’ Stories

A 61-year-old male presents with a 6-week history of jaundice, fatigue, weight loss, anorexia, nausea, and dry skin. During a telemedicine visit six weeks prior to his hospitalization, his primary care provider suggested that he likely had an infection. The patient is known to have a family history of cancer, including his deceased mother and father and sisters who were diagnosed in their late 30s. During his inpatient evaluation, a pancreatic mass is discovered. Regarding the course of events for this patient, the collective healthcare system’s (i.e., U.S. healthcare as guided by the Centers for Disease Control and Prevention, CDC) focus on preventative cancer care was somehow unfulfilled, particularly in light of his family history. Sadly, delays in diagnosis are known to contribute to higher costs. The average cost of initial diagnosis and treatment across all sites is \$43,516 according to the National Cancer Institute’s (NCI) 2020 estimates, with pancreatic cancer costs averaging \$108,165. An additional burden of delaying the diagnosis is the increased risk of mortality, which obviously affects how individuals are able to participate in the lives of their families, workplaces, and communities.

Another patient has been admitted to the intensive care unit for complications related to her metastatic bladder cancer. The 79-year-old woman has a history of hypertension, diabetes mellitus II, and atrial fibrillation with rapid ventricular rate. Her computed tomography (CT) scan showed possible fluid collection in her anterior abdominal wall and extensive metastatic disease in her chest, abdomen, and pelvis. As she moves forward with the necessary procedures to treat her symptoms, her comorbidities and disease progression will likely trap her in a cycle of post-acute care with each repeat admission taking its toll on her health, resulting in longer and costlier stays in hospitals and post-acute care facilities. Research has shown that health-related Navigating the Continuum of Care: Common Goods and Uncommon Experiences quality of life is negatively impacted by the financial distress of health care.⁵ Financial distress has outranked physical, emotional, social, and family distress, all of which can be exacerbated by the totality of consequences from the cycle of inpatient and post-acute treatment. For patients like this one, there exists a possibility for financial distress to feature prominently in perception of health-related quality of life as the new diagnosis cost for bladder cancer averages \$26,442 with continuing (yearly) costs of \$6,350. Considering the additional psycho-social supports and indirect cancer care costs suggests that a more comprehensive effort will need to be made to facilitate or make possible her overall well-being.

Finally, a 62-year-old female admitted to the oncology unit for abdominal pain and elevated sodium is known to have a history of liver cirrhosis with recurrent ascites, diabetes mellitus II, alcohol abuse, Chronic Obstructive Pulmonary Disease (COPD), hypertension, and lung cancer that required a lobectomy four years ago. During her admission, her liver pathology demonstrates findings consistent with moderately to poorly differentiated hepatocellular carcinoma that is determined to be unresectable. She was not able to complete the first line

⁵ See PDQ Adult Treatment Editorial Board, "Financial Toxicity and Cancer Treatment (PDQR): Health Professional Version," *PDQ Cancer Information Summaries* (Bethesda, MD: National Cancer Institute, 2021), www.ncbi.nlm.nih.gov/books/NBK384502/.

therapy because of her worsening liver function and has been told that she has reached the end stages of her disease process. The cost of liver cancer in the last year of life averages \$92,133. In light of the median household income of \$62,843, the treating end-stage liver cancer is largely cost-prohibitive for a majority of Americans. In most cases, costly life-prolonging treatments or clinical trials are pursued despite the fact that there is not a significant commensurate benefit (i.e., cure, palliation, significant life-extension, or improvement in health-related quality of life). Aggressive care plans at the end-of-life test the limits of health insurance (i.e., approval of therapies and interventions) and personal financial health often pushing patients toward the potential for bankruptcy.

Cancer Care and Its Costs

The downstream financial consequences for persons and families who are already socioeconomically disadvantaged are manifold. It is not uncommon that collective lost wages, depleted savings, and the brink of bankruptcy can lead to persons and families being displaced from housing. Additionally, the inability to absorb the continued costs, particularly in the end-of-life, proves deleterious for subsequent generations as the concomitant socioeconomic factors may continue to inhibit the possibility of financial health in the wake of aggressive cancer care. Though it is possible that portions of the financial burden can be mitigated through various cancer foundations and philanthropic organizations, the criteria for receipt of those funds are such that persons and their families must be close to dire financial straits. The reasons for the financial burden, aside from the direct costs of cancer care, are multifarious and linked to the social determinants of health and their causes. Unfortunately, authorized housing utility and food assistance through hospital foundations, and other assistance through private philanthropic organizations, cannot entirely mitigate the financially toxic burden of cancer care for individuals, their families, and by extension, their communities.

The totality of costs, direct and indirect, related to cancer care is staggering. With medical service and oral prescription drug costs in the U.S. approaching \$166,000 in direct care costs, the attention to the causes

and remedies for financial distress is needed. That need is further amplified because of the challenges in quantifying the indirect costs of care incurred by individuals and families resulting from lost wages, transportation costs, and the costs of additional caregivers. The detrimental cumulative effects of cancer care costs are often described using the term financial toxicity. Financial toxicity describes the ways in which the total financial burden of cancer care affects patients and their families, having first been used in 2013.⁶ The term encompasses many of the above-mentioned challenges, including adhering to treatment, quality of life, bankruptcy, and an increased risk of mortality.

While the experience of shockingly high billed charges is shared, the aggregate effects of the social determinants contributing to the inability to pay for cancer care are known to disproportionately affect marginalized persons and communities. Census data reveal that racial and ethnic minorities are more likely to be socioeconomically disadvantaged, live in substandard housing, and have less access to high quality health care. The data also reveal that they are more likely to have poorer health and specifically cancer-related outcomes.⁷ For example, unreliable transportation, which is directly related to time to diagnosis and adherence to treatment plans, can lead to increased costs associated with late-stage diagnosis (i.e., aggressive treatment and resulting inability to participate in daily activities).⁸

Not having adequate savings depends on one's employment status. Similarly, one's home environment can infringe upon one's ability to pay

⁶ See S. Yousuf Zafar and Amy P. Abernethy, "Financial Toxicity, Part I: A New Name for a Growing Problem," *Oncology (Williston Park)* 27, no. 2 (2013): 80–81, 149. See also S. Yousuf Zafar, Jeffrey M. Peppercorn, Deborah Schrag, Donald H. Taylor, Amy M. Goetzinger, Xiaoyin Zhong, and Amy P. Abernethy, "The Financial Toxicity of Cancer Treatment: A Pilot Study Assessing out-of-Pocket Expenses and the Insured Cancer Patient's Experience," *Oncologist* 18, no. 4 (2013): 381–390.

⁷ See PDQ Adult Treatment Editorial Board, "Financial Toxicity and Cancer Treatment (PDQR): Health Professional Version."

⁸ See Samina T. Syed, Ben S. Gerber, and Lisa K. Sharp, "Traveling Towards Disease: Transportation Barriers to Health Care Access," *Journal of Community Health* 38, no. 5 (2013): 976–993.

for cancer care as individuals and families choose between costly safe and health promoting homes or other less advantageous options. Additionally, healthcare literacy is linked to increased costs in cancer care. Choosing not to maintain routine wellness checks as a result of misinformation, lack of information, or a wellfounded distrust directed toward medicine almost certainly leads to increased costs later in the cancer care journey. Thus, the experience of financial burden is linked to additional social determinants of health. Financial toxicity and the distress born out of fear of financial hardship that plague individuals, families, and communities, often inter-generationally, will exacerbate the disproportionate burdens of those who unwittingly suffer from the systemic injustices that perpetuate the social determinants of health.

Prevention as Treatment

In order to achieve better health outcomes and mitigate the financial burdens associated with cancer care, cancer treatment is currently oriented toward prevention as the *treatment* for cancer. Much of the design of cancer care in the U.S. originates from the CDC's National Comprehensive Cancer Control Program (NCCCP).⁹ States are tasked with adapting the national framework to their local population needs and collaborating with local hospital systems and other agencies and organizations.

In Maryland, for example, lung cancer is one of the most commonly diagnosed cancers. From 2012 to 2016, lung cancer was the leading cause of cancer deaths, accounting for more than one quarter (25.1 percent) of all cancer deaths in the state. Thus, in Maryland, preventative efforts for reducing the occurrence of and deaths from lung cancer is a priority aligned to the NCCCP's goal of targeting cancers with the highest rates of incidence and mortality. With further refinement, state-based plans such as that of Maryland uncover who will benefit most from targeted preventative intervention. Secondary analysis in Maryland demonstrates

⁹ See Centers for Disease Control and Prevention, "National Comprehensive Cancer Control Program (NCCCP)," July 30, 2021, www.cdc.gov/cancer/ncccp/index.htm.

that lung cancer disproportionately affects African Americans, and specifically African American men. Therefore, efforts in Maryland, reflecting the goal of the NCCCP and state-based Maryland Comprehensive Control Plan,¹⁰ are directed toward reducing the incidence and mortality in lung cancer among African Americans. Supported by additional census and public health data, specific efforts to implement strategies aimed at mitigating the effects of the social determinants of health on this community were made. Secondary and tertiary aims such as reducing financial toxicity are outlined in the NCCCP.

Unfortunately, there are not specific mandates within the NCCCP for reducing financial toxicity, so it is incumbent upon the states to monitor and mitigate financial toxicity as best they can. In order to ensure success in mitigating cancer in a given community, coordination among various public and private institutions is required. The public-private and health system community partnerships are central while also highlighting opportunities for improvement.

Recently, Anne Arundel Medical Center¹¹ completed a lung cancer mitigation and treatment program in collaboration with local health departments and a private grant sponsor. The program was designed to improve the experience across the continuum of cancer care for at risk or diagnosed individuals in three counties by providing a multi-faceted approach to primary and secondary lung cancer prevention that integrated smoking avoidance and cessation, lung cancer screening services, and a Rapid Access Chest and Lung Assessment Program (RACLAP) intended to avoid delays in evaluation and consultation, cut down on unnecessary

¹⁰ See Maryland Department of Health, “Maryland Comprehensive Cancer Control Plan 2021–2025,” 2021, health.maryland.gov/phpa/cancer/cancerplan/SiteAssets/Pages/publications/Cancer-MD-Maryland_FINAL-1.pdf.

¹¹ Anne Arundel Medical Center, part of Luminis Health, is a 385-bed community hospital serving Annapolis (MD) and the surrounding area. In 2020, the medical center contributed more than \$61 million in community benefit, including subsidized programs and charity care, health education, and research activities.

procedures, provide timely feedback and information to the referring primary provider, and ensure patient and provider satisfaction.¹²

The RACLAP initiative offered interdisciplinary teams to patients and their families so that education, care planning, treatment, and support were provided in an individualized manner. Increased coordination in screening and care-plan development through RACLAP enabled the expansion of the program to minority patient populations whose use rate was incredibly low (10 percent) when compared to Whites (90 percent). In so doing, time-to-diagnosis was decreased, and more early-stage cancers were found when compared to historical marginalized group data.

These improvements likely resulted from increased awareness on behalf of providers who were motivated to refer to RACLAP patients with incidental findings. Cessation initiatives in inpatient care were also implemented during the program and have continued to include bedside interventions and substance abuse center collaboration. Mitigation or avoidance strategies also included education in schools, physician practices, community centers, campuses of large employers, and other venues. While the program was successfully based on the established participant, education, screening, and early identification goals, this program was only able to address one dimension of cancer care that contributes to marginalized groups not participating in cancer prevention or cancer care. The interrelated causes of financial toxicity and associated fear that weigh heavily in the community were reported but not resolved through the program's expanded use of nurse navigators and financial counselors. The health system's work to increase the number of free screenings, obtain co-payment assistance, coordinate transportation, and contribute to living expenses—common among cancer centers—were nominally effective in reducing certain financial burdens and related barriers to care. Surely, there are additional programs that have been

¹² See Bristol Myers Squibb, "Bristol Myers Squibb Foundation: Specialty Care for Vulnerable Populations," 2015, www.bms.com/about-us/responsibility/bristol-myers-squibb-foundation/our-key-initiatives/specialty-care-for-vulnerable-populations.html. Thanks to Catherine Brady Cupertino and Stephen Cattaneo, MD, and to Maria Christina M. Geronimo for her support in providing grant-funded program details.

equally or more successful in implementing strategies for reducing financial toxicity; however, the multifarious nature of the social determinants of health that influence financial toxicity presents an obstacle that likely exceeds the capacity of local hospital systems.

Addressing Financial Toxicity

Unfortunately, letting cancer patients experience severe financial distress or go into bankruptcy is part of the current healthcare system. Researchers have noted that this is simply not good for patients, physicians, and society,¹³ yet it remains the responsibility of local health systems to *fix* it. Enabling the participation of all persons—particularly persons whose cancer care experience is disproportionately burdensome because of the social determinants of health—is not attainable through the work of local health systems alone. Instead, a more comprehensive and systematic approach is needed to both identify the contributing causes of financial toxicity and propose trial remedies for them on a national scale.

The complex problem of financial toxicity requires an equally expansive strategy that includes all contributing persons and institutions. That strategy necessarily begins with the recognition that there is a shared responsibility in promoting the health and well-being of all persons—especially those who suffer disproportionately—and remediating the systemic causes of those burdens. In acknowledging and engaging the interrelated causes in interpersonal (i.e., provider-patient) and institutional (i.e., systemic forces that influence the cancer care experience) relationships, all persons can participate in cancer care. This systemic turn toward a health care delivery model that embodies truly solidaric practices and policies would be capable of generating the requisite changes in cancer care relative to the social determinants of health and financial toxicity.

¹³ See Diane Mapes, “Cancer, Bankruptcy and Death: Study Finds a Link,” *Hutch News Stories*, January 25, 2016, www.fredhutch.org/en/news/center-news/2016/01/cancer-bankruptcy-death-study-financial-toxicity.html.

Dr. Scott Ramsey of the Hutchinson Institute for Cancer Outcomes and Research¹⁴ has earnestly begun the work of enabling the equitable participation of all cancer patients through solidaric practices that offer systemic improvements.¹⁵ In collaboration with the National Cancer Institute's Community Oncology Research Program (NCORP) affiliated clinics, Ramsey's program is attempting to highlight and realize the importance of local and national (i.e., institutional) practices. In coordination with the NCI, the program, complete with dedicated financial counselors, is intended to provide data on the effects of financial toxicity and offer potential corrective measures in the form of new policies or practices. The belief is that open dialogue about cost concerns will illuminate the underlying causes of financial toxicity—causes that can then be remediated through policy and practice change across the healthcare system. A national project such as this reflects the importance of learning from persons and communities affected by current institutional policies and practices, and the need to enlist additional resources to the systemic sources of healthcare inequity.¹⁶ Should Dr. Ramsey's program, partnering with some 900 NCORP clinics, prove impactful in raising awareness and generating more substantive reforms, it will be the first step toward creating a more just healthcare system that enables equitable participation in cancer care.

¹⁴ The Hutchinson Institute for Cancer Outcomes Research (HICOR) is a research institute at Fred Hutch in Washington State. HICOR's mission is to improve cancer prevention, detection, and treatment in ways that will improve the clinical and economic outcomes of cancer care. HICOR hosts researchers, clinicians, patients, payers, and policymakers in the collaborative practice of data sharing to improve the totality of the clinical experience for all stakeholders. See Fred Hutch, "Hutchinson Institute for Cancer Outcomes Research," 2021, www.fredhutch.org/en/research/institutes-networks-ircs/hutchinson-institute-for-cancer-outcomes-research.html.

¹⁵ See Diane Mapes, "NIH Grant to Fund New Financial-Toxicity Intervention," *Hutch News Stories*, May 8, 2020, www.fredhutch.org/en/news/center-news/2020/05/nih-grant-funds-financial-toxicity-study.html.

¹⁶ See Diane Mapes, "How to Achieve Equity in Cancer Care, Research and Beyond," *Hutch News Stories*, September 25, 2020, www.fredhutch.org/en/news/center-news/2020/09/how-to-achieve-equity-in-cancer-care-research-and-beyond.html.

Conclusion

It will be important for other healthcare systems to design and implement similar programs with national scope, particularly not-for-profit systems that are known to provide care to underserved areas and persons. Obvious partners include Catholic health systems that frequently espouse the importance of honoring the dignity of persons, caring for the poor and marginalized, and facilitating the common good. Honoring the dignity of persons not only requires attention to and remediation of the systemic forces that contribute to the inequitable experience of financial toxicity but also more concerted effort on behalf of providers during their patient encounters. The social determinants of health may be outside the control of patients and providers but providing empathic care during individual patient encounter is well within the reach of all providers. This means providing culturally competent care that is attentive to personal values, beliefs, and concerns, which can subsequently ameliorate certain social determinants such as health literacy. It also means inquiring about various non-health influences that contribute to the health and well-being of patients. Doing so can help to identify and address the social determinants of health that have contributed to the patient’s illness or the patient’s inability to participate in care. Re-centering the provider-patient relationship in community programs such as Dr. Ramsey’s can further contribute to the necessary systemic changes as local health systems collaborate with national systems and structures. In such a way, more persons who have been marginalized can join in their cancer care. Structural reforms and a renewed focus on the person in context will better facilitate the promotion of the common good.

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