Ethical Challenges: Caring for the Underinsured, Geographically Disadvantaged Patient

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Vignette

Ms C is a 35-year-old woman from West Africa who came to the United States on a scholarship for international studies 7 years ago. Unfortunately, she developed debilitating glaucoma and was unable to continue her studies. She married, became a US citizen, had two children, and moved to southern Indiana. She does not have health insurance, because she is currently unemployed, and her husband works construction intermittently.

She develops a 2-month history of lymphadenopathy, fever, and night sweats and, despite several visits to physicians, continues to become more ill. Ultimately, she presents to an outlying hospital in Indiana. A cervical lymph node excisional biopsy is inconclusive. She is referred to the University of Louisville in Kentucky, because the referring physician suspects lymphoma. Given that diagnostic attempts were inconclusive, he urges her to be evaluated at an academic cancer center. Louisville shares the borders of the Ohio River with Indiana; thus, it is the closest academic cancer center to Ms C and the outlying hospital. Given her disability and two young children, Ms C is not able to easily travel to the University of Indiana (more than 2 hours away), which is often the typical academic referral route for a patient without insurance in the state of Indiana. Her physicians in Kentucky feel her presentation is most consistent with Hodgkin's lymphoma, and the pathology is sent for review to confirm the clinical suspicion. She is diagnosed with stage III Hodgkin's disease with unfavorable features.

Social work is consulted to expedite her Indiana Medicaid application once the diagnosis is confirmed as classical Hodgkin's disease. The patient and her oncologist are concerned that she will be left with medical bills that would financially devastate her. There are state funds and grants in each respective state that serve as a financial safety net in these situations. However, Indiana grants are not applicable to patients treated in Kentucky and vice versa. Ms C is also concerned that given her disability and her childcare needs, she will be unable to travel to Indiana University for further treatment. Although attempts are made to refer the patient to community-based oncology practices in southern Indiana who accept Medicaid, the patient is reluctant to transfer care away from the university. She feels there was an unnecessary delay in her diagnosis, and she is now desperate to start treatment.

Discussion

Oncologists are often faced with challenges that interfere with their ethical and professional obligations to provide the best medical care for patients who do not have the resources to pay for treatment. Physicians feel an ethical obligation to treat patients and uphold the Hippocratic oath, which states, "I will use treatment to help the sick according to my ability and judgment, but I will never use it to injure or harm them." Our beneficence is also outlined in the American Medical Association Code of Ethics, which states that physicians are obligated to provide "service with compassion and respect for human dignity."¹

Ethical conflict arises when financial and logistic factors place barriers between our view of the best possible medical care and the reality of the costs of cancer care.² As seen in this case, although public and private resources exist to support patient care,^{3,4} the type of care mandated by these systems may be impractical and could lead to inferior care. The purpose of this vignette is to explore the challenges associated with treating patients who are underinsured and have social factors that create barriers to optimal care.

In 2008, there were an estimated 46.3 million uninsured individuals in the United States, equal to 15% of the US population, as well as an additional 25 million underinsured individuals.^{5,6} In an effort to improve access to care, the Patient Protection and Affordable Care Act (PPACA) aims to expand health insurance coverage to 32 million individuals by 2019 through a variety of measures and would increase the share of legal nonelderly residents with insurance coverage from 83% currently to 94% when the law takes full effect. PPACA expands Medicaid coverage to include individuals with incomes up to 133% of the federal poverty level, thereby adding 16 to 20 million individuals to the Medicaid roster. This roughly translates to a potential 59% reduction in the number of uninsured. The law also provides credits and premium subsidies to low-income US citizens (up to 400% of the federal poverty level) who are not Medicaid eligible, so they can purchase insurance through state health exchanges.⁷ Although our patient Ms C would likely fall into one of these insurance groups, it is likely that the ethical challenge of where care is provided would remain. Additionally, the future of PPACA is uncertain, and its full application is several years away.

Although Medicaid expansion may improve access to health care, participants are generally required to receive care within their state of residence. Some states and counties also fund

cancer treatment programs for which underinsured patients may be eligible, but they too often require that participants be residents of the state or county sponsoring the program.⁸ Medicaid reimbursement varies significantly if the care is delivered outside the state of residence. For example, a \$5,000 claim from University of Louisville would typically be reimbursed approximately \$250 when treating a patient with Indiana Medicaid, which would often not cover the cost of the service. Thus, there is significant financial pressure to refer a patient to his or her home state, especially given the high cost of cancer care. However, in communities along state borders, requiring patients to receive care within their state of residence may place an undue geographic burden on patients, leading to suboptimal care. Additionally, as in cases similar to that of Ms C, a patient may desire to receive medical care at a university or specialized cancer center once a relationship is established. The extent of this issue is largely unmeasured, because most records of location of care and type of insurance are created by billed services, which would not capture patients rerouted to local or same-state cancer centers.

Although suburban community practices may have been an option for Ms C, given higher costs of health care and the current reimbursement environment, these options do not exist for all patients. The number of practices accepting Medicaid has declined over the last several years, although this varies from state to state depending on reimbursement structure. In 2008, physician practices were less likely to accept Medicaid than they were other insurance, including Medicare. Specifically, 53% of physician practices were accepting all or most patients with Medicaid, whereas 87% and 74% were accepting those with private insurance and Medicare, respectively. Minority physicians and nonrural and larger-group practices were more likely to accept all insurance. Episodic specialty care providers, such as surgeons, were also more likely to accept Medicaid, whereas longitudinal providers, such as primary care physicians and psychiatrists, were less likely.⁹ This is likely a result of reimbursement trends. Oncology is unique, given that often, initial episodic specialty care (such as adjuvant chemotherapy) as well as longitudinal care (such as surveillance) is provided, the latter of which may be financially challenging for local community practices, especially small rural practices. It is unknown how PPACA will affect this trend, because reimbursement rates specifically are not discussed.

Subspecialty care, such as bone marrow transplantation and complex surgical oncology, and specialized chemotherapy, such as high-dose interleukin-2, may pose a unique ethical challenge to the patient and provider. Unlike standard chemotherapy, as outlined in the vignette, these options may not exist in the community, and reimbursement rates are not higher if there is no local option. In these circumstances, there is an ethical obligation to treat the patient if no alternative exists; typically, a financial arrangement is established before therapy. However, in these instances, the patient is financially responsible for the remainder, and although the charge is often dramatically reduced, this translates into significant monetary loss and often unresolved debt.

This problem extends beyond Medicaid, because many patients with newly diagnosed cancer are not Medicaid eligible. In such situations, providers rely on funds such as the Disproportionate Share Hospital Program (DSH). This program is funded by federal and state governments for hospital care for indigent citizens of the respective states. This money is intended to offset the financial burden of providing medical care to those indigent patients ineligible for Medicaid and without insurance. The amount of DSH money a hospital receives is largely based on the expected cost of in-state indigent care for that provider per year. Thus, out-of-state residents are not budgeted for as part of this group. Furthermore, because a limited amount of money is dispensed once annually, many of the

Table 1. Cost of Cancer Care Resources

Resource
ASCO patient booklet "Managing the Cost of Cancer: Practical Guidance for Patients and Families" is available free of charge in booklet form as a printable PDF in English and Spanish; this booklet provides information to help patients and families understand costs related to cancer care, discuss cost with their health care providers, find financial assistance, and keep medical expenses organized
ASCO patient Web site Cancer.Net contains a number of additional resources to help patients

Abbreviation: ASCO, American Society of Clinical Oncology.

Table 2. Cultural Competency Resources

Resource
ASCO University: Quality Cancer Care for Minority Populations module
Cancer.Net resources; Cancer.Net en Español
Racial and Ethnic Disparities in US Health Care: A Chartbook www.commonwealthfund.org/usr_doc/Mead_raceethnicdisparities_chartbook_1111.pdf
A Physician's Practical Guide to Culturally Competent Care www.thinkculturalhealth.org
The Provider's Guide to Quality and Culture http://erc.msh.org/mainpage.cfm?file=1.0.htm&module=provider&language=English
Cultural Competence Self-Test (Matthews-Juarez P, Weinberg AD: Cultural Competence in Cancer Care: A Health Care Professional's Passport, 2004) http://iccnetwork.org/pocketguide/index.html
A Patient-Centered Guide to Implementing Language Access Services in Healthcare Organizations http://minorityhealth.hhs.gov/templates/content.aspx?ID=4375
Demographics and Health Care Access and Utilization of Limited-English-Proficient and English-Proficient Hispanics www.meps.ahrq.gov/mepsweb/data_files/publications/rf28/rf28.pdf
Schapira L, Vargas E, Hidalgo R: Lost in translation: Integrating medical interpreters into the multidisciplinary team. <i>Oncologist</i> 13:586-592, 2008
National Council on Interpreting in Health Care www.ncihc.org
CLAS standards http://minorityhealth.hhs.gov/templates/browse.aspx?M=2&MID=15
Literacy and Health Outcomes http://archive.ahrq.gov/clinic/epcsums/litsum.htm

Abbreviations: ASCO, American Society of Clinical Oncology; CLAS, culturally and linguistically appropriate services.

eligible hospitals run out of this funding well before the year ends.¹⁰ Local and state governments may provide additional resources not matched by federal funding to support hospitals providing indigent care. However, as with Medicaid and DSH, there are restrictions to the benefits by patient residence; patients who live outside the sponsoring county are often ineligible for benefits.

Hospitals and providers typically eligible for these types of additional funding are often referred to as safety-net providers. In 2000, the Institute of Medicine produced a report detailing the viability of US safety-net providers. A major concern was that as funding for Medicaid and related programs became more constrained, the use and dependency on the safety net grew.¹¹ Ten years later, this concern has only deepened with the economic downturn and the rising number of underinsured and uninsured individuals. Financial pressures on safety-net providers are growing, and this may be translated into less access to care for the geographically disadvantaged. Although PPACA may help lessen the number of uninsured, the Medicaid pool is expected to expand, which may add additional strain to safety-net providers and existing funding. As mentioned previously, PPACA has met with great debate and continues to be challenged. Given the uncertainty of the bill and thus of the health care structure in this country, preparing and budgeting for funding remain challenging. Without a dependable solution, the coverage gaps will continue to narrow access to care for those who are financially and geographically vulnerable.

There are resources to help with the cost of cancer care (Table 1). A patient's personal costs will depend on several factors, including the length and type of cancer treatment plan and the extent of health insurance coverage. Most relevant for the underinsured, these costs include copayments for office visits, radiologic studies, and laboratory work; cost of cancer treatment and supportive measures; cost of medical supplies and equipment (eg, ostomy and central venous access care); cost of transportation for the patient, caregiver, and/or dependents; cost of adult and/or child day care services; loss of income as a result of illness and medical appointments; and employment and legal issues pertaining to cancer diagnosis (eg, job discrimination, debt management, estate planning). Although groups such as the American Cancer Society and the Leukemia and Lymphoma Society are generous, with programs and grants to help assist in some of these costs, such as transportation, most of the financial burden outside of direct medical bills can go unassisted.

Another potential barrier to providing Ms C, a native of West Africa, the most optimal care is the issue of culturally competent care. The issue of cultural competence in the care of the underinsured is particularly important, because racial and ethnic minorities in the United States are more likely to be uninsured or underinsured.¹² Table 2 lists cultural competence educational resources available to oncology clinicians.

References

1. American Medical Association Code of Ethics. <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page>
2. Sulmasy DP: Cancer care, money, and the value of life: Whose justice? Which rationality? *J Clin Oncol* 25:217-222, 2007

Summary

Given the current fiscal and political environment in the United States, oncologists will likely find more challenges in caring for the underinsured. As increasing emphasis is placed on the affordability of health care, and as more cuts to Medicare and Medicaid loom on the horizon, we can anticipate more constraints in our ability to care for these patients. These financial and logistic constraints may come in direct conflict with our ethical obligation to provide optimal cancer care for vulnerable patient groups. Practical solutions to care for these patients are desperately needed. As this case demonstrates, reliance on local or state governments to address these problems is not the solution. A national solution to recognize and address underinsured and geographically vulnerable patients is needed. The entire oncology community will need to be at the forefront of these changes to help define the best strategies for overcoming these barriers.

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DOI: 10.1200/JOP.2012.000603.

3. US Department of Health and Human Services, Centers for Medicare and Medicaid Services: Medicaid eligibility. <http://www.cms.gov/MedicaidEligibility>
4. Jepson VA, Cox JV, Peppercorn J: Ethical challenges: Oncologists' role in immigrant health care. *J Oncol Pract* 6:247-248, 2010
5. DeNavas-Walt C, Proctor BD, Smith JC: Income, Poverty, and Health Insur-

ance Coverage in the United States: 2008. <http://www.census.gov/prod/2009pubs/p60-236.pdf>

6. Shoen C, Collins SR, Kriss JL, et al: How many are underinsured? Trends among U.S. adults, 2003 and 2007. *Health Aff (Milwood)* 27:w298-w309, 2008

7. Moy B, Polite BN, Halpern MT, et al: American Society of Clinical Oncology policy statement: Opportunities in the Patient Protection and Affordable Care Act to reduce cancer care disparities. *J Clin Oncol* 29:3816-3824, 2011

8. US Department of Health and Human Services, Centers for Medicare and Medicaid Services: State operations manual. http://www.cms.gov/manuals/Downloads/som107ap_v_emerg.pdf

9. Boukus E, Cassil A, O'Mally AS: A snapshot of U.S. physicians: Key findings from the 2008 Health Tracking Household Survey. <http://www.rwjf.org/qualityquality/product.jsp?id=47988>

10. Kentucky Administrative Regulations: 907 KAR 10:820. <http://www.lrc.ky.gov/kar/907/010/820.htm>

11. Lewin ME, Altman S (eds): *America's Health Care Safety Net: Intact but Endangered*. Washington, DC, National Academies Press, 2000

12. Henry J. Kaiser Family Foundation: *Health Insurance Coverage in America, 2008*. <http://www.kff.org/uninsured/7995.cfm>

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