Case Study: Samantha

Samantha is 44 years old and has been working as an accountant for the past ten years at a small firm, with 25 employees. When diagnosed with cancer, she had surgery and chemotherapy treatment for almost two years. She is still experiencing some fatigue, “chemo brain,” and some neuropathy in her feet. Due to these ongoing side effects, Samantha thinks that she may need to stop working. She is particularly concerned about what she is going to do for health insurance if she does take time off work for treatment and recovery since she has a preexisting condition. She is also worried about how she will afford to pay for her policy without a steady income.

I. Introduction

Health care spending accounts for 17.9 percent of the United States’ gross domestic product (GDP).1 According to the Centers for Medicare and Medicaid Services (CMS) Office of the Actuary, that number is expected to rise to almost 20 percent by 2022—totaling one-fifth of our nation’s GDP.2 Almost half of total U.S. health care spending is financed by the federal government through programs such as Medicare, Medicaid, and the financial assistance that is available to some individuals to purchase private health insurance. However, just having health insurance is not always

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sufficient to protect individuals from the often-devastating financial impact of a cancer diagnosis. One way to help mitigate the potential financial burden is for individuals to have adequate health insurance, to understand what is covered by their health insurance policies, and to know how their policies work.

Unfortunately, a vast number of Americans do not understand their health insurance policies. A 2014 study conducted by the Kaiser Family Foundation found that less than 50 percent of respondents could accurately calculate what they would have to pay for a hospital stay. Only 16 percent of respondents could calculate what they would be required to pay for a lab test if they had a policy with 60/40 coinsurance.\(^3\) Individuals with employer-sponsored health insurance also seem to lack basic understanding of their health insurance policies. A study commissioned by eHealth found that 50 percent of respondents were uncertain how much they paid for their monthly health insurance premiums and only 23 percent had a very good understanding of the terms used in their policies.\(^4\)

Needless to say, health insurance in this country is complex and multifaceted. Individuals diagnosed with cancer are typically thrown into a maze of issues, often left feeling as if there is no way out. The National Comprehensive Cancer Network states that psychosocial distress brought on by lack of information about cancer-related financial, legal, and practical issues should be recognized, monitored, documented, and treated promptly at all stages of the disease.\(^5\) Patients and caregivers are faced with navigating a complex health care system, which is often changing, and maintaining health insurance coverage to access quality health care.

Having access to adequate health insurance is not simply a financial issue, but it can have significant health-related consequences. The uninsured receive less preventive care and recommended screenings than the insured. In 2013, only 33 percent of uninsured individuals surveyed reported a preventive visit with a doctor in the past year, compared to 74 percent of adults with employer coverage and 67 percent of adults with Medicaid.\(^6\) Generally, those without insurance are less healthy than those with private coverage, and are at a higher risk for preventable hospitalizations and for missed diagnoses of serious health conditions (e.g., cancer).\(^7\) Furthermore, lack of follow-up care because of being without health insurance can delay the detection of

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cancer, which generally leads to a decreased quality of life and higher mortality rate. The American Cancer Society found that uninsured individuals had significantly increased likelihoods of advanced stage diagnoses, compared to those individuals with private health insurance. The Institute of Medicine report warned that failing to address employment, health insurance, and financial concerns may cause “additional suffering and threaten a patient’s return to optimum health.” This is especially relevant when discussing the needs of the young adult, low-income, minority, uninsured, or underinsured populations. For example, uninsured individuals may have new options for access to health insurance coverage, and without exposure to those options, they may be left confused, paying too much, or completely uninsured and unable to access health care.

Additionally, these types of psychosocial issues can be exacerbated by poverty. Another report indicated:

If poverty were treated as a “disease” then its “symptoms” or manifestations—absence of insurance, inability to afford co-pays for health care, limited access to primary health care providers . . . [and] the inability to take time off from work to access health care . . . must be dealt with in the context of improving the ability of poor . . . to receive . . . cancer screening, diagnosis, and treatment.

On March 23, 2010, President Barack Obama signed the Patient Protection and Affordable Care Act (ACA), also widely known as “Obamacare” or the Affordable Care Act. The ACA has two overarching goals: (1) to increase the number of Americans covered by health insurance; and (2) to decrease the cost of health care. This landmark law sought to improve the affordability and quality of health care in this country. Although every American benefits from the changes in the ACA, those with serious medical conditions, like cancer, experienced the most significant impact.

The ACA is a behemoth law stretching almost 1,000 pages itself, not including the regulations and guidance put out by various federal agencies. There are many provisions designed to work together to improve the system. There are four main federal agencies that are involved in implementing the provisions of the ACA: the U.S. Department of Health and Human Services (HHS), the U.S. Department of Labor

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8. Institute of Medicine, America’s Uninsured Crisis: Consequences for Health and Health Care 60–63 (2009).
11. For the purposes of this book, all references to the ACA actually refer to two separate pieces of legislation: the Patient Protection and Affordable Care Act (Pub. L. No. 111-148) and the Health Care and Education Reconciliation Act of 2010 (Pub. L. No. 111-152).
(DOL), the U.S. Department of the Treasury, and the Internal Revenue Service (IRS). These agencies have issued thousands of pages of regulations to date, and there will likely be more released in the coming years. Additionally, each state has taken a different route in implementing the ACA and has passed state laws, issued state executive orders, and released state agency regulations. The ACA made changes to many areas of the health care system—from payments to consumer protection. The political opposition to the ACA has been significant since its passage. Congress has tried 70 times to repeal or curb all or part of the ACA, and at the time of publication continues those efforts.

During 2017, nearly 10.3 million individuals had health insurance through the Marketplace. While the numbers vary depending on the source, approximately 9.1 million individuals received coverage through Medicaid following the ACA's expansion of the program, and the uninsured rate has dropped from 18 percent in 2013 to 11.7 percent in 2017. Many people with a cancer diagnosis have been able to access coverage that they were previously denied.

While the ACA brought some much needed, and widespread, changes to the U.S. health care system, improvements can still be made. This chapter seeks to explore the common topics that individuals coping with cancer face and guide them to additional resources to help navigate their health insurance options, rights, and benefits.

II. Definitions

The health care system in the United States has its own lexicon that can be very confusing to consumers.

A. Health Insurance Policy Terms

Health insurance policies will use terms to explain the coverage and costs they provide. Understanding these terms is critical for individuals to make the most of their policies.

- **Premium**: the monthly payment to have health insurance coverage. Individuals will pay this amount each month to have coverage, even if they never see a health care professional. It is similar to paying for car insurance all year, but never getting into an accident.
- **Deductible**: a fixed dollar amount that individuals are responsible for paying before their health insurance policy begins to pay for their health care. The amount of the deductible will depend on the plan. Plans may have a $0

Health Insurance

deductible and some may have a $5,000 deductible. For example, if Rachel’s
deductible is $1,000, her plan will not pay for her covered medical expenses
until she has paid $1,000 for covered health care services subject to the deduct-
ible. This is also referred to as “meeting the deductible.” However, it is impor-
tant to note that deductibles may not apply to all services (e.g., some preven-
tative services) and that not all out-of-pocket payments will count towards a
deductible (e.g., some plans do not apply co-payments towards the deductible).

- **Coinsurance or cost-share**: the difference in what the insurance company will
  pay for an individual’s medical expenses and what the individual pays for the
  medical expenses. For example, Ross has an 80/20 plan that has an allowed
  amount for an office visit of $100. If Ross has met his deductible, his coinsur-
  ance payment of 20 percent would be $20. The health insurance plan pays the
  remaining 80 percent.

- **Co-payment**: a fixed dollar amount individuals pay for a covered health care
  service, usually at the time of service (e.g., visit the doctor or obtain a prescrip-
  tion drug from a pharmacy). The amount can vary by the type of covered
  health care service and can be anywhere from $1 to upwards of $250.

- **Out-of-pocket maximum**: a fixed dollar amount that caps how much individu-
  als are responsible for paying out of pocket during a policy period (usually one
  year). After individuals reach that cap, the health insurance policy pays 100
  percent for covered essential health benefits (EHBs) for the rest of the year.
  This limit includes deductibles, coinsurance, and co-payments made towards

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**Out of Pocket Maximum Example**

Simone falls off a ladder and she has to go to the emergency room and then spend
a week in the hospital that is in her policy’s network. She ends up with a $102,000
hospital bill. How much of that bill is Simone actually responsible for?

Simone’s health insurance plan has an emergency room co-pay of $250, a deduct-
ible of $2,000 and an 80/20 cost-share. The plan has an out-of-pocket maximum of
$4,000.

First, Simone must pay her co-pay of $250 at the time of the emergency room visit.

Next, she has to pay her deductible of $2,000. She is now left with a $100,000
balance.

Because Simone has met her deductible, the insurance company will pay 80 per-
cent of the bill and she is responsible for 20 percent—or $20,000.

However, Simone’s plan has an out-of-pocket maximum of $4,000. Remember, she
has already paid $250 in co-payments and $2,000 in deductibles, which means that
she will only have to pay another $1,750 out of pocket. The health insurance com-
pany will have to pay the remaining balance.
EHBs. This limit does not include premiums, balance billing amounts for non-network providers, other out-of-network cost-sharing, or spending for non-EHBs. With some limited exceptions, the maximum out-of-pocket cost limit for any Health Insurance Marketplace plan for 2018 can be no more than $7,350 for an individual plan and $14,700 for a family plan. Some types of health insurance policies are not required to have an out-of-pocket maximum, including short-term health plans, Original Medicare (i.e., Parts A and B), and grandfathered health plans.

B. Other Health Insurance Concepts

There are a few other concepts that are helpful for individuals to understand as they are shopping for and using their health insurance coverage.

- **Provider network**: most insurance plans have a specific network of providers, doctors, hospitals, pharmacies, and other health care professionals from which individuals can receive care. In exchange for being part of the network, the provider has agreed to a certain payment rate from the insurance company. Individuals who receive care from a provider in their insurance company’s network will be charged the negotiated payment rate. If individuals receive care from providers outside their insurance company network, the insurance company will cover less or none of that care, depending on the type of plan.

- **Prescription drug formulary**: list of prescription drugs that a health plan will cover and for how much. Understanding and using a plan’s formulary will help individuals save money on their medications. With some formularies, individuals will pay the same amount regardless of the drug they receive. However, some plans have formularies with two or more cost levels, or tiers. The higher the tier, the more the drug costs the individual. Generic drugs typically cost less than brand-name drugs, some brand-name drugs may cost more than others, and some are not on the formulary at all.

- **Grandfathered plans**: a health insurance policy that was in existence on or before March 23, 2010. Plans will lose their grandfathered status at any time if they make substantial changes to the plan, such as significantly cutting benefits or increasing out-of-pocket spending for policyholders. Practically, the only grandfathered plans still in existence are large group-sponsored plans (e.g., plans for hospital employees). Some of the ACA’s consumer protections will not apply to grandfathered plans.

C. Types of Health Insurance Plans

There are three main places from which individuals obtain health insurance: directly from a health insurance company; from an employer; and from the government, primarily through Medicare, Medicaid, and the military.
The most common types of plans are health maintenance organizations (HMOs) and preferred provider organizations (PPOs). Both types of plans use a network of providers to offer the highest quality care. However, there are a couple key differences between HMOs and PPOs.

- **HMO**: a type of health plan that employs or contracts with health care professionals, such as doctors and hospitals, to create a network of participating providers. There are two main types of HMOs:14 (1) an HMO facility (e.g., Kaiser) and (2) an HMO plan, where individuals pick a primary care physician, who acts as a “gatekeeper.” In other words, all of the individual’s health care services go through that doctor. Generally, that means that individuals need a referral before they can see any other health care professional, except in an emergency. Visits to health care professionals outside of the HMO’s network are typically not covered or covered at a very low rate. For example, if Janet has a skin rash, she would not go straight to a dermatologist. First, Janet would see her primary care physician. If that physician cannot help Janet, she will get a referral to a trusted dermatologist in her network. The benefits of coordinating your health care through a primary care physician are less paperwork and lower health care costs for everyone. However, in exchange for a lower cost, an HMO typically offers less choice in providers and less control.

- **PPO**: a type of health plan that contracts with health care providers, such as hospitals and doctors, to create a network of participating providers. Policyholders pay less if they use providers that belong to the plan’s network. However, they may have the option to use doctors, hospitals, and providers outside of the PPO’s network for an additional cost. For example, a PPO plan may have an 80/20 cost-share for in-network care, but may also have a 50/50 cost-share for any care received out-of-network. With a PPO, individuals are not required to have a primary care physician and they can see any health care professional, even specialists, without a referral. Typically, PPOs have higher monthly premiums than HMOs. However, individuals may need fewer appointments to get the care they need in that they do not need to visit a primary care physician first and there is more choice with respect to providers.

- **Exclusive provider organization (EPO)**: a plan that is similar to a PPO, where individuals have a network of doctors and hospitals to choose from. However, unlike with some PPOs, an EPO will not pay for any services obtained outside of the network. In other words, there are no out-of-network benefits.

- **Fee-for-service (FFS)**: a plan that reimburses individuals as health care expenses are incurred.15 With these types of plans, a provider is paid a fee for each service provided (e.g., each MRI is billed separately). These are the types of

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plans that primarily existed before the rise of HMOs and PPOs. With FFS plans, the individual pays a predetermined percentage of the cost of health care services, and the insurance company (or self-insured employer) pays the other percentage. For example, an individual might pay 30 percent for services and the insurance company pays 70 percent. The fees for services are defined by the providers and vary from physician to physician. While FFS plans offer individuals the freedom to choose their health care providers, over the course of a long treatment for an illness like cancer, these separate charges can lead to a significant expense.¹⁶

- **High-deductible health plans (HDHP):** plans that have a minimum deductible of $1,350 per year for individual coverage and $2,700 for family coverage in 2018.¹⁷

- **Consumer-directed health plans (CDHP):** a type of health plan that allows individuals to pay for routine health care using a health savings account (HSA) (see Section II.D), but also covers them through an HDHP, should they experience a major medical diagnosis, like cancer.

One type of health plan is not necessarily better than another. Individuals should consider their personal needs and the options available to them in their area when it comes to choosing a plan.

Some health insurance companies also sell short-term plans. While these plans may have a lower monthly premium, individuals should be very wary of these plans. They are not required to provide the consumer protections included in the ACA and they are able to deny selling to individuals and exclude treatments for preexisting conditions, like cancer. Additionally, many of them have very high out-of-pocket costs for minimal coverage, costing individuals more in the long run. These plans are also not considered credible coverage since they are not required to renew coverage. This means that if these plans end midyear, then it does not trigger a special enrollment period (SEP) to buy a marketplace plan, which may leave some uninsured.

### D. Types of Health Insurance Accounts

In addition to a health insurance policy, there are some financial accounts that may help individuals pay for health care.

- **Flexible spending accounts (FSAs):** a savings account where the money in the account is used to pay for health care expenses such as deductibles, drugs, and

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other out-of-pocket costs. FSAs are only available with employer-sponsored health insurance policies. If an employer offers an FSA, employees are able to set aside a portion of their salary to fund the FSA, and the money contributed to an FSA is not taxed. An employee can choose how much he or she wants to contribute each pay period, up to a maximum of $2,650 per year in 2018. Generally, money that is contributed to an FSA must be spent on qualified health care costs that year. However, employees are able to carry over up to $500 per year to use in the next year. Alternatively, employers have the option to offer a “grace period” of up to 2.5 extra months to allow individuals to spend any remaining funds in the FSA. After the grace period or year, individuals forfeit any money left unspent in the FSA. However, FSA funds cannot be used to pay insurance premiums.

There are several advantages to FSAs. For instance, the account is pre-funded, so individuals have immediate access to the funds for that calendar year. In other words, if an individual has a large medical bill at the beginning of the year, the FSA will cover it even if the individual has not contributed that amount yet. Additionally, dependents can be covered under a Dependent Care FSA, and money contributed to the FSA by the parent is not taxed. Some disadvantages of FSAs include losing unused money remaining in an FSA account at the end of the year, having difficulty in estimating how much money to put into an FSA, and needing to keep track of all FSA-eligible expenses in order to be reimbursed from an FSA.

- **HSAs**: a type of savings account where the money in the account is used to pay for certain health care costs. This plan was created in 2003 for adults under the age of 65 who are covered by an HDHP. In 2018, an HDHP is one with a deductible more than $1,350 for self-only coverage or $2,700 for family coverage. Individuals could use their HSAs to pay bills until they reach their deductible or use the funds to pay for co-pays and other health care expenses. Individuals are able to establish an HSA through a financial institution, or their employer may offer an option for an HSA. The money deposited in the account is not taxed. It is important to note that in order to use HSAs, the HDHP must be the individual’s only health insurance plan. However, having vision, dental, disability, or long-term care insurance does not preclude individuals from establishing an HSA. In 2018, the maximum amount individuals could contribute to an HSA was $3,450 or for a family policy up to $6,900. Unlike an FSA, funds contributed to HSAs roll over and accumulate year to year if they are not spent.

20. Id.
To determine whether an HSA would be beneficial, individuals should consider their budgets and potential health care needs for the upcoming year. Some advantages of HSAs are that individuals are able to determine the amount of money to set aside for health care costs, they control how the HSA money is spent, and they are not required to pay taxes on money contributed to an HSA. However, the disadvantages to HSAs are that it is hard for individuals to predict when they will get sick, many individuals do not have extra funds to contribute to an HSA, and if money is withdrawn for nonmedical expenses, individuals will be taxed. For more information on HSAs, visit https://www.treasury.gov/resource-center/faqs/taxes/pages/health-savings-accounts.aspx.

Understanding these health care terms and concepts can help individuals when purchasing the most appropriate policy for their needs, as well as effectively utilizing their coverage when getting medical care.

III. Care for the Uninsured

In 2013, an estimated 44 million people lacked health insurance coverage. That number has decreased with the passage of the ACA; however, 28.2 million Americans are still uninsured according to a 2016 Kaiser Family Foundation report. Of those individuals without insurance, 24 percent had incomes below the federal poverty level (FPL). Thus, while it seems somewhat obvious that the “poor” struggle with the affordability of health insurance, because of the high cost of health insurance, this problem expands well beyond those with limited incomes. Other large populations that remain uninsured include noncitizens (both lawfully present and undocumented immigrants). Undocumented immigrants and legal immigrants residing in the United States for less than five years are ineligible for federally funded health coverage (e.g., Medicaid and the Children’s Health Insurance Program (CHIP)) except in emergency situations. However, since 2002, states have had the option to provide prenatal care to women who are undocumented and can extend CHIP coverage to their children. Additionally, there are some state and locally funded health programs that provide coverage to individuals regardless of immigration status.

Individuals who do not qualify for, or cannot afford, health insurance have very limited options to access health care. They have three main options for accessing health care: federally funded health centers, community clinics, and emergency departments.

22. Id.
23. Id.