ANNALS OF HEALTH LAW
Advance Directive

VOLUME 22 SPRING 2013 PAGES 1-13

Coverage Capped when You Need it Most: The Effect of Lifetime Insurance Limits on Cancer Patients

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I. INTRODUCTION

Cancer is a deadly, all-consuming disease. In 2009, it trailed only heart disease in the number of people it killed, at over 500,000 deaths in the United States alone.[1] Those who survive are faced with medical care that is exceedingly expensive.[2] As medical science improves, and new cancer treatments create a better survival rate, more and more people will be living with cancer. Currently, there are approximately 12.5 million people in the United States living with cancer[3] and more than 1.6 million are expected to be diagnosed in 2013 alone.[4] While many people view cancer as a death sentence, the five-year survival rate is now at sixty-eight percent up from forty-nine percent between 1975-1977.[5] This improved survival rate can be

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1. Melonie Heron, *Deaths: Leading Causes for 2009,* 61(7) NAT'L VITAL STATISTICS REP. 1, 9 (2012).

2. In the United States, cancer care is among the most expensive treatment plans. *See* Marilynn Marchione, *Cancer's Growing Burden: The High Cost of Care,* USA TODAY (Feb. 27, 2012), *available at* http://usatoday30.usatoday.com/news/health/story/health/story/2012-02-27/Cancers-growing-burden-the-high-cost-of-care/53271430/1.

3. Nat'l Cancer Inst, *SEER Stat Fact Sheets: All Sites,* WWW.CANCER.GOV, http://seer.cancer.gov/statfacts/html/all.html (last visited Feb. 18, 2013). These statistics include any living person as of January 1, 2009, who had been diagnosed with cancer at any site prior to January 1, 2009. *Id.* This also includes any persons with active disease and those who have been cured. *Id.*

4. AM. CANCER SOC'Y, CANCER FACTS & FIGURES 2013 1 (2013), http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-036845.pdf.

5. *Id.* at 2. This rate does not distinguish between cancer in remission and those still in treatment and cancer deaths can still occur more than five years after diagnosis. *Id.*

attributed to a number of factors, including early detection and improved treatment techniques.[6] While this progress is encouraging, it is causing increased financial hardships on families faced with paying for long-term care.

In 2008, the overall medical costs of cancer in the U.S. totaled $77.4 billion.[7] That collective number, while staggering, does little to paint a picture of the costs for the average patient. From patient to patient, costs vary dramatically. Factors such as the patient's type of cancer, the patient's complications, and the doctor's treatment decisions all contribute to the costs.[8]

Faced with such high costs, even insured individuals have difficulty paying their medical bills and medical bankruptcies have become prevalent in the U.S.[9] Many of these individuals find themselves facing a "double disaster:" being sick and dealing with a bankruptcy.[10] A 2009 clinical research study found strong connections between high medical bills and bankruptcy.[11] Before the financial crisis, in 2007, using the most conservative definitions, sixty-two percent of all bankruptcies were medical.[12] It is not just the patient that is affected by high medical costs, the

6. *Id.*
7. *Id.* at 3.
8. *See* Marchione, *supra* note 2.
9. *See* Elizabeth Warren, *Sick and Broke*, WASH. POST, (Feb. 9, 2005), *available at* http://www.washingtonpost.com/wp-dyn/articles/A9447-2005Feb8.html.
10. *Id.*
11. *See* David U. Himmelstein, et al., *Medical Bankruptcy in the United States, 2007: Results of a National Study*, AM. J. MED. 1, 2 (2009).
12. *Id; but see* Erika Gonzalez, *Patients Go Bankrupt As Medical Costs Soar*, COLO. PUB. NEWS, (May 21, 2012), http://www.pnhp.org/news/2012/may/patients-go-bankrupt-as-medical-costs-soar. Other studies have found lesser connections between medical bills and bankruptcies. A Northwestern University study found that just 17% of bankruptcies were medical related and a U.S. Department of Justice study between 2000 and 2002 found just 13% of bankruptcies to be medical. *Id*. Of a sample of bankrupt individuals, 57.1% had high medical bills, 5.7% of homeowners had mortgaged their homes to pay medical bills, and 40.3% had lost income due to illness. Himmelstein, et al., *supra* note 11, at 3.

whole family suffers.[13] Nearly seventy-five percent of the bankrupt individuals were insured and most were middle class and educated.[14] Despite this relative affluence, the average out of pocket medical expense for those with insurance was $17,749.[15]

Compounding the financial strain on families coping with cancer, many insurance plans have both a yearly and lifetime limit for the amount of coverage they will expend.[16] With a high-cost disease such as cancer, many patients routinely exceed those limits, and are quickly faced with high out of pocket costs.[17] This causes families to face tough financial decisions, including rationing what type of care they can afford.[18] However, by 2014, as part of the Patient Protection and Affordable Care Act (PPACA), insurers will no longer be able to include these yearly and lifetime caps on coverage.[19]

Unfortunately, the elimination of lifetime limits on healthcare coverage will do little to reduce medical costs for the average cancer patient. Only rare, outlier patients with exceedingly high medical costs and low lifetime limits will really benefit financially from this provision. On the other hand, the emotional freedom afforded by no longer having to take into account lifetime limits is important and immeasurable.

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13. *Id.* In the same study, 77.9% of the patients were either the debtor or the spouse, a child caused 14.6% of cases, and 7.5% of the cases were a parent, sibling, or other adult patient. *Id.* at 4.

14. *Id.* at 3.

15. *Id.* at 4.

16. Lifetime limits are caps placed on coverage in many insurance plans that stipulate a maximum total dollar in benefits that the insurer will pay over a patient's lifetime. PRICEWATERHOUSECOOPERS, THE IMPACT OF LIFETIME LIMITS, 2 (2009), http://www.hemophilia.org/docs/LifetimeLimitsReport.pdf. Once a patient reaches their lifetime limit, they no longer receive any coverage from their insurer and are essentially "uninsured." *See id; see also* discussion *infra* Section II.

17. *See* Reed Abelson, *Awaiting Health Law's Prognosis*, N.Y. TIMES, (Feb. 1, 2011), http://www.nytimes.com/2011/02/02/business/02insure.html?pagewanted=all.

18. *See id.*

19. Patient Protection and Affordable Care Act, 42 U.S.C. § 2711 (2010) [hereinafter PPACA].

This article will begin with a detailed explanation of lifetime limits in Section II. Section III will discuss the costs of cancer and the effect of lifetime limits on average cancer patient, and Section IV will discuss the elimination of caps under the PPACA.

II. LIFETIME LIMITS

A lifetime limit, in the health insurance context, is a stipulation in an insurance plan that puts a dollar limit on the amount of benefits patients can receive in their lifetime.[20] After patients reach their lifetime limit, their health insurance will no longer pay them benefits.[21] Insurers implement these provisions as a cost cutting move[22] in order to limit the amount paid for their most expensive clients. In a typical insurance plan, lifetime limits are assessed on an individual, "per-person" basis;[23] thus if one member of a family exceeds his or her lifetime limit, and lost his or her coverage, the rest of the family would be unaffected and still be covered. In a typical insurance plan, these provisions can be hard to find, but they are often listed as the "Maximum Lifetime Plan Benefit"[24] or "Lifetime Maximum."[25]

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20. PRICEWATERHOUSECOOPERS, *supra* note 16. These figures were based on a PriceWaterhouseCooper survey of health insurance lifetime limits. *Id.* In this study, "PwC researched the public domain for survey and reports on lifetime maximum distributions and cost. The overall estimates were based on the 2007 Kaiser Foundation Annual Survey Report on Employer Health Benefits." *Id.*

21. *Id.*

22. *See* Requirements for Group Health Plans and Health Insurance Issuers Under the Patient Protection and Affordable Care Act Relating to Preexisting Condition Exclusions, Lifetime and Annual Limits, Recessions, and Patient Protections, 75 Fed. Reg. 37, 187, 37,206 (June 28, 2010) (to be codified at 26 C.F.R. pt. 54) [hereinafter Requirements for Group Health Plans]. Eliminating these caps will lead to higher costs for the insurer, so naturally they were put in place to keep costs lower. *Id.*

23. *See* BLUE CROSS BLUE SHIELD, BCBS HIGH DEDUCTIBLE HEALTH PLAN (2009), *available at* http://www.bcbsnc.com/assets/members/public/pdf/progressenergy/2009 BCBSNC_High_Deductible_Health_Plan.pdf.

24. *See id.*

25. *See* CIGNA HEALTHCARE, SUMMARY OF BENEFITS: YOUR HEALTH SAVINGS ACCOUNT QUALIFIED-OPEN ACCESS PLUS PLAN (2010), *available at* http://www.cigna.com/assets/ docs/information-for-small-group-brokers/HDHP_1-90.pdf.

Generally, all medical, mental health, substance abuse services, and prescription drugs benefits count towards the patient's lifetime limit.[26]

Not all insurance plans contain a lifetime limit provision and the dollar amount of the cap varies from plan to plan.[27] Approximately ninety-one million people are covered by an employer health insurance plan subject to a lifetime limit,[28] which is about fifty-five percent of people with employer-provided insurance.[29] In 2009, it was estimated that 20,000-25,000 people reached their lifetime limit.[30]

When patients reach their lifetime limit, they are no longer covered by their insurance plan, and are "essentially uninsured."[31] Once they reach their lifetime limit they have a variety of options; they can pay out of pocket[32] or limit their future healthcare costs, often by changing their treatment plan to one that is cheaper or experimental.[33] In addition, a patient may switch insurance plans to reset his cap.[34] This can be accomplished either by switching employers, buying into a new plan, or if he works for an employer with multiple plan options, switching plans.[35] Potentially, a patient could also "spend down" his assets and qualify for federal medical assistance through Medicaid.[36] While these options may be viable for certain individuals, many patients do not have the flexibility to

26. *See* BLUE CROSS BLUE SHIELD, *supra* note 23.
27. PRICEWATERHOUSECOOPERS, *supra* note 16, at 3. About 1% of insurance plans have a lifetime limit of less than $1 million; 22% of plans have a cap of $1 million, but less than $2 million; 32% of plans have a limit of $2 million or greater; while 45% of plans have no lifetime limit (unlimited). *Id.*
28. *Id.*
29. *Id.* at 1.
30. *Id.* at 3.
31. Requirements for Group Health Plans, *supra* note 22, at 37,205.
32. PRICEWATERHOUSECOOPERS, *supra* note 16, at 2.
33. *See* Abelson, *supra* note 17, at 2.
34. Requirements for Group Health Plans, *supra* note 22, at 37,220.
35. *Id.*
36. PRICEWATERHOUSECOOPERS, *supra* note 16, at 2.

switch jobs at will or do not have an employer that offers multiple plans.[37] It can take several months or even years to spend down their assets in an effort to qualify for Medicaid.[38] Thus, even if a patient had the option to switch insurers or qualify for Medicaid, he could still experience a gap in coverage[39] and potentially miss treatments.[40] Furthermore, the care beneficiaries do receive may be of a lower quality, and they may have to switch to an unfamiliar doctor or hospital when they switch insurers.[41]

However, patients cannot wait until they reach the limit to begin planning; they need to decide early on in their treatment how to ration their care to ensure they do not lose treatment when they need it most.[42] In addition, many health insurance plans do not inform patients until they have reached their lifetime limit.[43] Thus, cancer patients are often required to track expenses on their own to predict when they will reach their lifetime limit. All of these factors place not just a significant financial burden, but also a severe emotional burden on a patient. A cancer patient is already facing an all-consuming disease, and must also make decisions through the lens of lifetime limits. These lifetime limits put an additional strain on care decisions, and require patients to focus not simply on getting well, but also take into consideration costs based on how long they will be treated, or more practically, how long they will live.

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37. JEANNE M. LAMBREW, "CHOICE" IN HEALTH CARE: WHAT DO PEOPLE REALLY WANT? 3 (2005), *available at* http://www.commonwealthfund.org/usr_doc/lambrew_853_choice_ib.pdf. Only 53% of working-aged adults with employer provided healthcare have a choice between two or more health plans. *Id.*

38. PRICEWATERHOUSECOOPERS, *supra* note 16, at 2.

39. Requirements for Group Health Plans, *supra* note 22, at 37,207.

40. *See id.* at 37,205.

41. *See* Abelson, *supra* note 17, at 3.

42. *Id.*

43. *See* KARYN SCHWARTZ, ET AL. SPENDING TO SURVIVE: CANCER PATIENTS CONFRONT HOLES IN THE HEALTH INSURANCE SYSTEM 32 (2009), *available at* http://www.kff.org/insurance/upload/7851.pdf.

III. THE COSTS OF CANCER

Despite the high financial costs of cancer, it is unlikely that the average patient will ever reach his or her lifetime limit. While there has been no formal study conducted, a recent survey indicated that only ten percent of cancer patients had reached their lifetime limit.[44]

Using average cancer costs, one can better grasp this issue's prevalence. The average annual cost of cancer for an insured patient varies widely based on type of cancer.[45] For patients over the age of sixty-five, this can range from about $5,000 per year for melanoma to $110,000 per year for brain cancer.[46] Overall, brain, pancreas, esophagus, ovary, and stomach cancers have the largest annualized initial cost, while melanoma, breast, and prostate cancers have the lowest annualized initial cost.[47] In addition, costs tend to be higher in the first year of treatment and in the patient's final years,[48] and vary by gender.[49] For patients under the age of sixty-five, annual costs for the first year's treatment range from around $6,000 for melanoma to nearly $140,000 for brain cancer.[50] The average annual co-pay for cancer patients under the age of sixty-five tends to lower in the interim years, and then rise in the final year of treatment.[51] Older patients

44. Susan Jaffe, *The New Health Care Law and Annual and Lifetime Coverage Limits*, AARP.ORG (Aug. 23, 2010), http://www.aarp.org/health/health-care-reform/info-08-2010/hcr_explained.html.

45. *See* Angela B. Mariotto et al., *Projections of the Cost of Cancer Care in the United States: 2010-2020*, 103 J. N CANCER INS. 117 (2010), http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3107566/pdf/djq495.pdf. For this study, cancer costs were estimated using Medicare claims SEER data. *Id.* at 118.

46. *Id.* at 125.

47. *Id.*

48. *Id.*

49. *Id.*

50. *Id.*

51. The average annual co-pay cost for the first year of treatment is $62,238. *Id.* In the intervening years, this lowers to $5,891, but in the last year of life, the costs are again much higher, with an average cost of $138,538. *Id.*

face slightly lower costs, overall.[52]

Using these figures, it seems unlikely that most cancer patients would reach their lifetime limits. Under average figures it would take an individual who started treatment at age sixty-five or older approximately 161 years to reach his or her lifetime limit of $1 million.[53] A patient who was under the age of sixty-five in his or her first year of treatment would take 159 years to reach his or her lifetime limit of $1 million.[54] Even using the most generous figures, it would take a male brain cancer patient, who began treatment under the age of sixty-five, over ninety-one years to reach his lifetime limit of $1 million.[55] Thus, the average cancer patient is unlikely to have to grapple with lifetime limits.

Despite this, outlier costs can be significantly higher. Drug costs can be a major factor in someone exceeding his or her lifetime limit, and may significantly raise their out of pocket costs. For example, Zytiga, a prostate cancer medicine approved last year, costs $6,100 a month.[56] Insured patients have reported paying as little as $1.50 per month and as much as $5,943 copayment.[57] Meanwhile, Neulesta, a shot that boosts white blood cells to help patients better tolerate chemotherapy, can cost as much as $14,865.[58] Some insured patients have reported paying as much as $12,000 for the shot, while others have reported paying less than $7,000 in copayments.[59] Neither of these cost nearly as much as the most expensive

52. For the first year of treatment, the average annual cost for a patient over the age of sixty-five is $52,303. *Id.* This levels out to a more reasonable average annual cost of $5,891 in subsequent years. *Id.* In the last year of life, the costs rise significantly again, with an average cost of $94,473. *Id.*

53. This assumes they do not pay the higher "final year" costs. *Id.*

54. This assumes they do not pay the higher "final year" costs. *Id.*

55. This assumes they do not pay the higher "final year" costs. *Id.*

56. Marchione, *supra* note 2.

57. *Id.*

58. *Id.*

59. *Id.*

cancer drugs—Bexxar and Zevalin, used to treat rare forms of Non-Hodgkins Lymphoma – which cost nearly $25,000 per treatment.[60]

With drug costs at this level, an individual could quickly surpass their lifetime limit. For instance, the American Cancer Society interviewed several cancer patients coping with high medical bills, including ten-year-old Taylor Whilhite.[61] Taylor was diagnosed with Acute Myeloid Leukemia and doctors prescribed an aggressive treatment program.[62] Subsequently, "[s]he received three rounds of chemotherapy and a bone marrow transplant; at one point she was taking twenty-three pills a day in addition to IV medications."[63] In addition, the cancer caused numerous side effects including heart problems, hip problems, diabetes, and a compromised immune system,[64] which required further treatment. Even at the young age of ten, Taylor reached her lifetime limit of $1 million.[65] Her parents were able to secure an increase of their lifetime limit to $1.5 million, but that was not enough to cover the surgeries and treatment she needs.[66] Her family has decided to rely on HIPAA[67] coverage upon exhausting their lifetime limit, at a great expense to them.[68]

Furthermore, patients that have not reached their lifetime limit still worry about rationing their care for fear of reaching their lifetime limit. For

60. Alex Berenson, *Market Forces Cited in Lymphoma Drugs' Disuse*, N.Y. TIMES (Jul. 14, 2007).
61. *See* Schwartz et al., *supra* note 43, at 32.
62. *Id.*
63. *Id.*
64. *Id.*
65. *Id.*
66. *See id.*
67. HIPAA is the Health Insurance Portability and Accountability Act which offers insurance individuals who have exhausted their normal coverage. *See* CTR. FOR MEDICARE AND MEDICAID SERVICES, HIPAA ELIGIBILITY CRITERIA FOR INDIVIDUAL COVERAGE 1, *available at* http://www.cms.gov/Regulations-and-Guidance/Health-Insurance-Reform/HealthInsReformforConsume/downloads/HIPAA_Eligibility_Criteria.pdf.
68. Schwartz et al., *supra* note 43, at 32.

example, Judy Lamb, who was interviewed during an HHS article series on the PPACA, had breast cancer that spread to her liver and bones.[69] She had a lifetime limit of $2 million, while her care cost between $250,000-$500,000 a year.[70] At that rate, she knew that she would soon exceed her lifetime limit, and needed to ration her care.[71]

Patients may also alter their care decisions for fear of reaching their lifetime limits. For example, Hillary St. Pierre, who was interviewed by the New York Times about the effect of the PPACA on her health care choices, had Hodgkin's lymphoma, and was close to reaching her lifetime limit of $2 million.[72] She received a bone marrow transplant, which failed, but her insurance was going to run out before she could receive a second.[73] To receive further chemotherapy, she was forced to enroll in a clinical trial for an experimental treatment.[74] She was also forced to consider a variety of options for her medical care including divorcing her husband, so she could qualify for Medicaid, or moving to Massachusetts, where there is universal healthcare.[75]

While most patients will likely never have to deal with their coverage being capped, all three of these patients were faced with changing their care plan or risking the loss of insurance coverage. The elimination of these caps will allow patients like them to focus more on getting well and on the best treatment plan for their health, rather than on what will contribute the least to their lifetime limit. Nonetheless, the elimination of lifetime limits

69. *Dori Salcido, Judy-Care: Focusing on Fighting Cancer, Without Fear of Lifetime Insurance Caps, HEALTHCARE.GOV (May 22, 2012), http://www.healthcare.gov/blog/2012/05/mycare_judy.html.*
70. *Id.*
71. *See id.*
72. Abelson, *supra* note 17.
73. *Id.*
74. *Id.*
75. *Id.*

will have little effect on the average cancer patient.

IV. THE PPACA AND LIFETIME LIMITS

By 2014, the PPACA eliminates annual and lifetime limits on health insurance.[76] Specifically, any healthcare plan started or renewed after September 23, 2010 may not put any lifetime limit on coverage.[77] Furthermore, annual limits will be slowly phased out, and any insurance plan purchased or renewed by January 1, 2014 will have no annual limit.[78]

In addition, it is likely that eliminating lifetime limits will have only a modest effect on individual insurance premiums, adding about one percent to the cost.[79] On the group market, the percentage will be even less, at just 0.5%.[80] Furthermore, because there will be fewer people losing their insurance due to lifetime limits, there will be fewer people joining Medicare and Medicaid, which should alleviate some of the stress on those programs.[81] Thus, for most insured individuals, the cost increases in their insurance should be slight.

When drafting this law, Congress aimed to ensure that people had health insurance when they needed it most. Government regulations note that: "prohibiting lifetime limits and restricting annual limits assures that insurance will perform the function for which it was designed—namely, protecting health and financial well-being for those most in need of care."[82] Congress offered that banning lifetime limits was a basic safeguard to

76. PPACA, *supra* note 19.
77. U.S. Dep't of Health and Human Servs., *Lifetime & Annual Limits*, HEALTHCARE.GOV, http://www.healthcare.gov/law/features/costs/limits/index.html (last updated Jan. 24, 2012).
78. *Id.*
79. Abelson, *supra* note 17. If a plan has a $1 million limit, eliminating that cap would cause a rise of 1% to the premium. *Id.*
80. Requirements for Group Health Plans, *supra* note 22, at 37,216.
81. *Id.* at 37,206.
82. *Id.* at 37,205.

ensure that families were not arbitrarily denied healthcare coverage,[83] and believed that the ban would save families money.[84] In addition, Congress stated they believed it to be only fair that citizens have the same benefits afforded to members of Congress, who do not have a lifetime limit on their insurance plan.[85]

Taking all of these goals into account, it seems that eliminating lifetime limits is an easy choice to make. This program does not cost the average insured person much, and it helps eliminate what has been a source of anxiety and worry for many patients with chronic illnesses. However, few cancer patients actually reach their lifetime limit, and therefore, removing the lifetime cap does not go far enough to significantly help families facing medical bills. A more comprehensive package needs to be put into place that brings costs down in every aspect of healthcare. It is the high cost of medications, doctors, treatments, prescriptions, and everything in between that is leading to the financial strain on the average cancer patient. If Congress truly wants to save families coping with cancer money, it must do more than simply eliminate lifetime limits. While banning lifetime limits is a good start that will help those with the highest medical bills, it does little to alleviate the financial strain on the average cancer patient.

V. CONCLUSION

While it seems unlikely that the average cancer patient would need to worry about reaching their lifetime limit, health insurance coverage caps still affect many individuals. Aggressive treatment plans and expensive cancer drugs, coupled with earlier detection, have led to rising costs. But

83. 111 CONG. REC. S7407-09 (daily ed. Sept. 23, 2010) (statement of Sen. Robert Casey).
84. 111 CONG. REC. S9697 (daily ed. Sept. 23, 2010) (statement of Sen. Jeff Merkley).
85. 111 CONG. REC. H1459 (daily ed. Mar. 16, 2010) (statement of Sen. Robert Andrews).

for the new PPACA provisions, many more individuals would likely have reached their limit in the next decade. The elimination of lifetime and annual limits does not necessarily eliminate a cancer patient's need to worry about the costs of treatments. On the contrary, co-pays can still be very high and vary widely from person to person and treatment to treatment. What the prohibition of these caps does guarantee is that cancer patients will never have to fear their coverage will run out just because they are pursuing an aggressive treatment plan or have complications with their treatment. They will no longer have to budget their treatment based on how long they think they may live. It may just be one less thing they have to worry about, but for many patients, it is key.