

What is the True Cost of Cancer?

The new technologies and treatments that are being used to better understand and fight cancer, its causes, and its treatments are groundbreaking. There are increasingly more efficient, effective, and less painful ways to combat cancer and the mortality rates have successfully been decreased by 20% in the last ten years¹ for people who get to experience the benefits of all these treatment options. However, the increasing complexity and efficacy seem to come with as increasing price and a lot research shows that less and less people are being able to experience the benefit of these amazing treatments because they cannot afford them. When things are more expensive, not as many people will be able to pay for it; the issue is clearly logical and real even though some data about it might not yet be conclusive and still needs further research. Medicine has saved countless millions of lives and should be accessible to everyone, but admittedly it still is a profit-maximizing business that people make millions of dollars off of, which is something that will never be changed. However, sustaining a strong and prosperous economy is not inconsistent with having affordable cancer care. Because of the drastically increasing cost of cancer and increasing frequency of the disease, society's expenditure that is now necessary to study and treat the disease has become astronomical. Actions need to be considered and taken in order to figure out what is causing this escalation of price and reduce the cost that is necessary for cancer treatment, which would therefore increase the accessibility of treatment for everyone.

An increasing variety of different expenses are now making cancer more expensive than ever. Cancer is by far the most expensive health condition that costs billions and billions of dollars each year. The overall cost of cancer in 2010 was \$157 billion and is projected to be \$174 billion in 2020². The cost of cancer is expected to rise around 2% every year³, equated to be thousands of dollars per cancer patient in many cases. This can be attributed to cancer drugs that can cost over \$10000 per month and many therapies that can cost upwards of \$30000⁴. Even with good insurance, many people end up having to pay around half of these costs, which is money that so many people just do not have. In 2005, direct medical costs (out-of-pocket) for patients were \$74 billion⁵, which undoubtedly has risen in more recent years. While this amount of money necessary for treatment may seem staggering and is regularly unreachable for a significant amount of the population, it does not even begin to encompass all the costs that cancer patients must face. There are many additional, often smaller costs that are not covered by insurance- referred to as "hidden costs"- that often get overlooked by many people and that add up to be a huge financial burden. Many uninformed people believe the connotation that only the chemotherapy, radiation treatment, or over-night hospital fees are where the bulk of the cost comes from, however, that is only a portion of the makeup. For example, separate non-prescribed over the counter medications, extra x-rays and screenings, transportation to and from the hospital, food preparation services, payment for at home care workers, and legal worker fees to

¹ Dr. Sucharu Prakash

² "Cancer Prevalence and Cost of Care Projections"

³ "Cancer Prevalence and Cost of Care Projections"

⁴ Sollitto, Marlo, Sherlin, Margarets, and LifeRyder. "Cancer Patients: Going Broke to Stay Alive."

⁵ Metropol, Neal, and Kevin Schulman. "Cost of Cancer Care: Issues and Implications."

deal with problems and potentially write the will are just some of the big underlying costs that people do not realize they have to save up for⁶. Most of these hidden costs are not aided by insurance either, so people often must scavenge for some way to pay for them or be forced to use money they desperately need for other necessities instead. All of these hidden costs pay for things that are obviously very important contributors to the treatment and recovery processes, but many people don't get to take advantage of all these possibilities because they cannot afford to pay for them. Receiving these "extra" benefits can often make a person's recovery much faster and less painful. While seemingly a small and arbitrary concept, they can play a vital role in treatment. The enormity of the hidden costs is an idea that everyone needs to understand so they can prepare for them in case they need to pay for them, or at least further empathize with and assist people who do. Not much is being done to advertise that cancer will be a lot more expensive than expected, but at the very least this misunderstanding needs to be resolved so people can have a better chance at being able to afford these. If people knew exactly what they were dealing with, a fundamental step towards actions being taken to reduce the cost of cancer would be taken.

Furthermore, a growing number of people are now having to pay these costs because of the increasing frequency of cancer diagnoses, which just amplifies overall expenditure and consequences more people. In 2016, almost 1700000 new cases were diagnosed and it was determined that a shocking 39.6% of all men and women will contract some form of cancer during their lifetime⁷. Cancer costs and its debt are becoming more widespread, just another reason why actions need to be taken to support all those affected. The idea that the prevalence of cancer is becoming almost a regularity should be drawing more attention because it shows that there is a shockingly likely chance that cancer really could affect someone themselves, or likewise anyone they know during their lifetime. People that are in a position of power with respect to determining drug and treatment prices, such as insurers and drug companies, need to be understand these statistics, because once they are further made aware of how likely it is that this may directly affect them or a loved one, they could be much more likely to act to make treatments more affordable. With the increasing frequency and increasing costs, it's becoming too pervasive and too damaging to ignore. Around 50% of families with a child who is diagnosed with cancer will go bankrupt. Additionally, one out of four families will spend their entire life savings on cancer recovery treatment⁸. The rising costs of cancer are negatively impacting too many families to discount. The physical suffering caused by the actual disease is more than enough for cancer patients and their loved ones to deal with, and understandably it cannot be controlled to a very large extent. Likewise, the likelihood of developing most cancers are very often predisposed and cannot be controlled either, granted there a few exceptions. However, if people work together to reduce the costs, which there is some element of control over, unlike the likelihood of contracting it, it may make the recovery process significantly less stressful and traumatic.

While the monetary costs are obviously devastating, the social and nonmonetary costs are massive as well. There are said to be 25 separate social costs that affect the victims, their family

⁶ "Understanding the Costs Related to Cancer Care."

⁷ "Cancer Statistics." *National Cancer Institute*

⁸ Heller, Garrett

and colleagues, and their caregivers⁹. Productivity loss is one of the biggest nonmedical costs. People may have to quit their jobs because they don't have time to work since they are dealing with either their own treatment or a family member's. This just leads back to the monetary problems because they no longer have a strong and reliable source of income. This is difficult to measure and obviously can vary greatly depending on the individual person, their career, and their specific case which is why it often disregarded, but one study was done on the nonmedical costs by measuring wage rate. In 2005, the annual mean cancer-related wage loss was \$17729¹⁰, which would even be a more inflated number today. In many cases, this incoming money is all that people have to pay for treatment, and without it they have no options. Along with this loss of productivity, is the idea that people straightforwardly lose time. In 2003-2006, the average time lost due to cancer related activities after diagnosis was 13.7 months and 8.3 hours per day for people with colorectal cancer, which isn't even in the top five most-costly kinds of cancer. The time cost for it ranged from \$26363 to \$50060. The opportunity cost of the time that it takes to travel for treatment, appointments, etc is massive as well; the mean monthly out of pocket travel costs were between \$213 and \$372¹¹. Patients are often spending hundreds of dollars before they even get to the hospital. It is appalling how much of a "commitment" cancer is. While this exact data may or may not be definitive and exact, the general trend of all the costs becoming more expensive is clear. The magnitude of the productivity and time loss alone is very convincing. People are sacrificing tens of thousands of dollars and countless hours just to deal with social costs, which doesn't even pay for their actual treatment or help put their cancer into remission. It is not appropriate to expect people to deal with this one their own.

On top of all this is the fact that people may not get to experience a "normal" life, as cancer hurts their social and emotional well-being. People often get labeled with a stigma of having cancer and their lives change entirely because of this. They may not have the same social opportunities and may not have many chances for recreation, which just adds to the toll on their body and mind. Patients often deal with body-image issues, fear and grief of recurrence, problems with relationships, loss of spirituality, and "survivor guilt"¹². The existence and severity of all these conditions is vary variable and is another thing that is impossible to measure, but the negativities that are brought about by them are clear. All these costs may stress people out and make the quality of their life much worse, which could arguably be considered as bad or even worse than financial costs. These can even make the physical symptoms worse because some patients develop depression and anxiety¹³. Because people have to "pay" all these nonmonetary costs as well, the idea of reducing the actual financial costs should be examined in order to relieve the patients in some way and diminish the risk of worsening their condition, and the first step in doing this would be to identify what exactly is causing this expensiveness.

⁹ Metropol, Neal, and Kevin Schulman

¹⁰ Yabroff, Robin, Laurel Borowski, and Joseph Lipscomb. "Economic Studies in Colorectal Cancer: Challenges in Measuring and Comparing Costs."

¹¹ Yabroff, Robin, Laurel Borowski, and Joseph Lipscomb.

¹² "Social and Emotional Impacts of Cancer and Cancer Treatment." *Oregon Health & Science University*.

¹³ "Social and Emotional Impacts of Cancer and Cancer Treatment."

There are numerous factors that lead to this high prices of cancer treatment and drugs but most significantly is the extreme difficulty, unreliability, and astronomical expense of getting new cancer drugs approved and the uncontrolled monopolies that many companies have over certain types of drugs that they can use to over-price. There are basically three major reasons why the cost of cancer and the drugs used to treat it are increasing so much and so quickly¹⁴. First, drugs are currently getting approved to be used in treatment if they have a statistical benefit that has been shown in laboratory studies, even if they are clinically unimportant in actual treatments. However, these drugs are still sold and purchased, which solely increases the absolute cost of treatment to society. The second is that because of this unpredictable variability with the effectiveness of newly-approved drugs and how expensive it is to get clinical acceptance- the average cost of approval for a drug is \$1.6 billion¹⁵- insurance companies understandably have to increase premiums and sometimes reduce coverage to keep up with the cost of care in the industry. This increases insurance rates which multiplies the costs put on the patients. Between 2003 and 2004, 25% of patients who had costly private insurance plans still had at least \$5000 in out-of-pocket expenditures, not to mention their pricey premium fee on top of this. Then third, a lot of the drugs that are approved are eventually used to treat certain conditions in ways that they were not approved for by the FDA, but still offer a marginal benefit for. When using the drugs in this "off label" way, the price of treatment is increased because patients will purchase the drug based off recommendations from health care workers, even though it offers little to no use; this practice of extra useless drugs being prescribed is becoming more common. Doctors will recommend drugs that are not directly designed to help with the specific type of cancer or reduce the exact symptoms being experienced, but that may incidentally or unintentionally help fight the disease in some way. Even if they're intentions are good and they're genuinely trying to help the patient in any way that they can, the overall effect of "off-label" drug use just increases expenditure on the patient. These three reasons are not the fault of anyone, but they just seem to be flaws in the medical care industry that appear like they could be resolved.

In addition, monopolies that many companies hold over certain types of drugs lead to uncontrolled, soaring drug prices. Cancer is an incredibly complex and unique disease and all of its varieties require very specific science and individualized drugs to combat them, limiting many corporations from getting involved in drug production. Because most people receiving chemotherapy as their main treatment unfortunately tend to die off from their disease at some point, there is no competition among cancer drug companies to lower their cost to compete with it. This enables the companies that do partake in drug production to financially prosper¹⁶. They can advertise certain drugs to help with particular things that may be totally unique in purpose giving them a monopoly in that specific type of treatment and outcome. When the patient finishes their cycle of that drug, whether it did help temporarily reduce symptoms or not work at all, they will then start subsequent options until they've used all the drugs available (or until

¹⁴ Siddiqui, Mustaqeem, and S. Vincent Rajkumar. "The High Cost of Cancer Drugs and What We Can Do About It." All subsequent uncited facts in the paragraph are from this source.

¹⁵ Heller, Garrett.

¹⁶ Siddiqui, Mustaqeem, and S. Vincent Rajkumar.

they're totally cured, which is usually unlikely as most forms of cancer are actually incurable¹⁷). Companies know that at one point or another, regardless of their price, there is a good chance that the patient will try their drug, even if they start with a cheaper option, because they are fighting for their life. This keeps prices very inelastic and resistant to change. A study showed that doubling the price of a specialty cancer treatment only lead to a 1% decrease in consumers spending on it. People feel pressure to buy drugs that have some potential to help them for their life-threatening condition, regardless of the price. While drug companies absolutely do have the right to make a profit off this, many do take advantage of patients and lack of regulation in the system. Some balance of ethics needs to be found and enforced. If nothing is changed in drug policies and pricing, as well as the limitation of monopolies, there is no evidence that suggests treatment effectiveness and accessibility will improve because there is no incentive for the drug companies to decrease their prices.

There are several effective measures that could be taken to ease cancer's expense on patients. One major, admittedly very theoretical, way that would help accomplish this is by moving away from the current fee-for-service payment model in cancer treatment. This current model creates a financial incentive for doctors to administer multiple, more expensive treatments that may not always be necessary because they get paid based on the quantity of treatments administered. In a study done from 1995-1998, physicians who were reimbursed for their treatments by Medicare using the fee-for-service model tended to use significantly more-costly treatment options¹⁸. Not surprisingly, these physicians studied did what they could to make more money, which is not a misconduct by any mean but can be viewed as immoral. Instead of educating patients about how effective these drugs actually may be and letting the patients weigh the costs against the rewards and make the decision themselves, they essentially prescribed all the options they could. Obviously not many hospitals are intentionally putting profit over the well-being of the patient, however, it is clear that there is this issue of unnecessary quantity and therefore price of treatment. Instead of this payment system, a value-based pricing system with bundled reimbursements appears like it would be a successful alternative. In this, the price of a drug would be correlated to its direct effectiveness and doctors would be reimbursed based on the quality of their care and treatments altogether, not the quantity like in the current payment model. The effectiveness of the drug would be based on Quality-Adjusted Life Years, which is the number of additional years that the drugs would add to the patient's life. Quality of life, "is affected by the efficacy and toxicity of the therapy and is determined based on standardized measures, such as time trade-off, the standard gamble method, willingness to pay, visual analog scales, EuroQol's EQ-5D questionnaire, the Quality of Well-being Scale, or the years of healthy life measure. In general, these measures include assessments of vision, hearing, mobility, cognition, speech, pain, dexterity, and emotion."¹⁹ Using QALYs provides a very concrete, objective qualification, unlike the subjective and inconsistent existing criteria, to be approved and will strengthen the quality of drugs that are put into market. As of now, the FDA approves drugs based on their safety and clinical benefit shown in lab studies, so if they are shown to increase survival by only a few days and follow health regulations they would get approved. If a drug could be funded and had these two things it would be approved. New standards need to be

¹⁷ Siddiqui, Mustaqeem, and S. Vincent Rajkumar.

¹⁸ Siddiqui, Mustaqeem, and S. Vincent Rajkumar.

¹⁹ Siddiqui, Mustaqeem, and S. Vincent Rajkumar.

made that are based on the drugs actual magnitude of benefit, not just by their ability to buy their way through the approval process. When this, as well as the value-based pricing system is established, patients potentially won't have to pay as much but will still receive very adequate treatment. While granted it could be argued that there would not be as many transactions per patient and the drug companies would stand make slightly less money, the exponential benefit that the patients would receive from the new payment model would far outweigh some minimal profit loss for already prosperous companies.

More so, price controls could be established on drugs that monopolize their variety. Again, drugs that are very special and unique in their nature can afford to be marked up in price because they may be the only option for a patient. If the prices of these drugs were held so that they could only have a certain profit margin, it would prevent a single drug from dominating the field and decrease barriers to entry for other companies²⁰. This will create more competition which will lead to prices being lowered further and higher quality drugs being innovated. This should be doable as many other countries have already done it. Germany recently established the Pharmaceutical Market Restructuring Act, in which the unbiased Joint Federal Committee negotiates the prices of new drugs coming into the market²¹. Admittedly, it is still too soon to see what exactly will happen with the policy, but it has thus far been very successful in making drugs more affordable and accessible. More so, in 2012, there was a private drug in India used to treat renal and liver cancer that was incredibly cost prohibitive, but that many people needed. The government gave a license to a generic company to develop a lower-cost version of the same drug, which had amazing results in decreasing patient expenditure. Brazil has successfully implemented similar licensing policies, as well. Despite the fact that these countries don't stack up to the United States economically, some aspects of their medical care seem to be much more progressive through these very practical policies. With all the benefits the United States has seen these other countries experiencing, it may be time to learn start trying to reach a higher level of patient care. Currently, the Affordable Care Act is the best working policy that is attempting to decrease medical costs in the United States, and it is taking steps to "curb insurance company abuses"²². It essentially requires everyone to purchase health insurance and subsidizes households with lower incomes with premium tax credits. It has successfully helped the 46.3 million individuals in 2009 who had inadequate health care and greatly reduced that number²³, but it hasn't really established price controls. It doesn't focus on cancer care and it is expected that "removing or lessening the entrepreneurial incentives from the providers will not reward true efficiencies of care and will stifle innovation of new drugs, devices, and therapies"²⁴. While it may help on the insurance side of general healthcare, it doesn't seem as if it will have a big impact on reducing the monetary and nonmonetary costs of cancer or advancing the quality of medical care in any way. Yet, it still is a step in the right direction and shows that people are

²⁰ Siddiqui, Mustaqeem, and S. Vincent Rajkumar.

²¹ Siddiqui, Mustaqeem, and S. Vincent Rajkumar.

²² Pariser, David M. "Ethical Considerations in Health Care Reform: Pros of the Affordable Care Act."

²³ Pariser, David M.

²⁴ Pariser, David M.

starting to notice the issue and are trying to help, just possibly not in the most effective ways right now.

A well-known and very knowledgeable figure who embodies all these upright ideals about the respectable trade-off between price and availability is George Merck, the president and chairman of Merck & Co., a very major pharmaceutical companies. He gave a very influential speech in which he talks about how the industry must be improved: “We cannot afford to remain static, because, if we do, we soon would be going backward and find ourselves overtaken by competitors”²⁵. He has profited extremely well from the industry and would continue to prosper financially with the current system, yet still admits that someone must act to change the industry. He says that more people in the industry need to ask themselves: “What is the right thing to do?”²⁶. Clearly different people would have very different responses regarding this question, but the message Merck wanted to make clear is that, “We try to remember that medicine is for the patient. We try never to forget that medicine is for the people. It is not for the profits. The profits follow, and if we have remembered that, they have never failed to appear”²⁷. He was never making decisions in his business solely for the purpose of making money, he always tried to do what was actually best for the patient and their health. He even acknowledges that this is an unrealistic model, but just wants people to ponder it when making decisions about how to treat a patient. His mindset on this topic is one that should be embraced and if it were truly put into practice patients would likely be happier and feel more secure about their situations. Merck can be viewed as a trailblazer in the industry by posing the question, “How can we bring the best of medicine to each and every person?”²⁸

Obviously in an ideal world, cancer treatment would be free and everyone would have an equal chance to get the best treatment and the whole process would be as easy and stress-free as possible. Clearly, this is unfeasible, though and this is an incredibly complex question. There is this huge ethical dilemma of profits against the patient’s well-being and it is something that will never go away. There are many facets of cancer and its treatment, though, that seemingly could be changed to make everything easier on the patient without ruining the whole business side of medicine, but it is still unclear exactly how to go about this process. Whether the identified problems and the suggested solutions are sufficient or not, in one way or another, something needs to be done that can reduce the burden of all the costs and negativities, allowing cancer patients to focus on finding some positive meaning to their experience. Cancer has this association with devastation and death, and hopefully it’s connotation of expense and bankruptcy will become just as widespread and well-known. Although there are countless negativities that it brings about, people who contract it often seem to find some meaning out of the experience, such as strengthening relationships. In order to enable victims of this tragic disease to find a positive skew within their situation, the whole process needs to be made as worry-free for them as possible. Evidently, an ideal way to do this is to make sure the patient knows they are receiving the best treatments and know they are maintaining financial security. While there is so much

²⁵ Merck, George. "Medicine Is For the Patients, Not For the Profits."

²⁶ Merck, George.

²⁷ Merck, George.

²⁸ Merck, George.

ambiguity in the field of cancer, one of the few things that is concrete is that the whole experience should cost less.

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