Addressing Cancer's Financial Toxicity:

How Access to Free Legal Care Helps to Overcome Barriers to Care for Minnesota Cancer Patients Caused by Health Insurance and Provider Billing Issues

By Cancer Legal Care

How Access to Free Legal Services Helps to Address Cancer's Financial Toxicity

Defining the issue

A national study found that 42% of all newly diagnosed cancer patients over age 50 will deplete their life savings within two years of diagnosis. (1) Cancer Legal Care's average client age is 56.

While often studied, there are rarely practical, real-time solutions for addressing financial toxicity. One way is by making free legal care services available and accessible to all cancer patients and survivors.

Why?

1. The cause of a cancer patient's financial devastation is often something a lawyer can help turn around.

Cancer Legal Care staff and volunteer attorneys provide legal care help on issues involving employment, government benefits, housing, creditor matters, and insurance coverage. These are the very issues at the heart of nearly every cancer patient's financial stressors regardless of their pre-cancer earning capacity/employment, insurance status, or housing security.

2. Many people with cancer don't have the financial ability to pay for a lawyer's help.

Without the resources to hire an attorney to help with the legal issues outlined above, financial issues and the attendant stress they bring continue to grow, compound, and intertwine. A free resource, open to all, like Cancer Legal Care, is vital in addressing them.

3. A lawyer's help is often what's needed to make a cancer patient's medical care possible and ensure that insurance covers the costs it should.

Insurance denials don't just impact health outcomes, they derail finances, sometimes for decades, when expensive cancer treatments are not covered by insurance.

The impact

After Cancer Legal Care's insurance appeals attorneys succeeded in getting nearly $20,000 of denied cancer treatments paid in full by her insurance company, one grateful client wrote:

"*An enormous financial burden and stress has been lifted from me, and **I feel that I can breathe and live again.***

*I am quite certain that **I could not have achieved these frankly amazing results on my own.***

***Thank you for all that you do** for me and others facing similar situations in the cancer community.*

It is with this type of help that I will continue to thrive."

(1) Death or Debt? National Estimates of Financial Toxicity in Persons with Newly-Diagnosed Cancer
Adrienne M. Gilligan, PhD ,David S. Alberts, MD ,Denise J. Roe, DrPH , Grant H. Skrepnek, PhD , Published: June 12, 2018DOI: https://doi.org/10.1016/j.amjmed.2018.05.020

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Introduction

Issues with health insurance coverage and provider billing errors create barriers to care for Minnesota cancer patients because the primary consequence of these issues is the financial strain they create for patients. When facing a prohibitively large bill or a treatment that they cannot afford out of pocket, many patients delay or abandon their treatment, opt for a potentially less effective treatment, or avoid seeking care altogether. Timely and free legal care can overcome these barriers by restoring a patient's insurance benefits or protecting a patient's finances from erroneous medical charges. Access to free legal care is necessary because most people with cancer simply do not have the financial ability to pay for a lawyer's help, compounding the prevalence of financial toxicity in the patient's life.

Financial Toxicity – the Added Burden of Cancer

Financial Toxicity is defined as "the detrimental effects of the excess financial strain caused by the diagnosis of cancer on the well-being of patients, their families, and society."[1] Financial toxicity is reflected in very startling statistics, including:

- Cancer patients are, on average, 2.5 times more likely to file bankruptcy than those without cancer. Furthermore, cancer survivors who file for bankruptcy are 80 percent more likely to die than cancer patients who do not.[2]
- 62 percent of personal bankruptcies filed are due in part to significant medical debt. Yet, of these bankruptcy filers, 78 percent had health insurance.[3]
- 14 percent of Minnesotans are insured by high deductible insurance plans – nearly twice the national average.[4]
- 79 percent of oncology care providers are concerned with their cancer patients refusing treatment because of financial worries, and 49 percent have had a cancer patient refuse treatment because of a financial concern.[5]
- From 2003-2006, more than two million cancer survivors in the United States did not get one or more needed medical service because of financial concerns.[6]

Statistics are not the only reflection of the weight of financial toxicity on a patient. One of our clients with a health insurance issue once told us: *"Everyone keeps saying 'focus on the medical, focus on the medical and get better.' I can't focus on the medical when I have all of this going on."* Another client, whose spouse was the family's main income earner and passed away from

[1] Aakash Desai, Bishal Gyawali. Financial toxicity of cancer treatment: Moving the discussion from acknowledgment of the problem to identifying solutions. EClinicalMedicine. 2020 Mar; 20: 100269.
[2] Mapes D. Cancer bankruptcy and death: study finds link. Fred Hutch News Service. January 25, 2016.
[3] Himmelstein DU, Thorne D, Warren E, et al. Medical Bankruptcy in the United States, 2007: Results of a National Study. The American Journal of Medicine. 2009;122:741-746.
[4] Spencer J. More Minnesotans driven to choose high-deductible health insurance. Star Tribune. June 6, 2012.
[5] Highlights from the 2018 Trending Now in Cancer Care Survey. Association of Community Cancer Centers, Oncology Roundtable.
[6] Weaver KE, Rowland JH, Bellizzi KM, Aziz NM. Forgoing medical care because of cost: assessing disparities in healthcare access among cancer survivors living in the United States. Cancer. 2010 Jul 15;116(14):3493-504. doi: 10.1002/cncr.25209. PMID: 20549763; PMCID: PMC3018838

cancer, was left with over $50,000 in cancer treatment bills after a series of health insurance denials for his wife's treatment. He told us that having to pay those bills would "wipe him out" financially, leaving him without means to afford a home and daily living expenses for his three small children.

Recognition of financial toxicity and the effect it has on the well-being of patients is crucial not only because of the fact that it devastates the economic footing of the patient and their family, but also because financial toxicity prevents the results of medical interventions and treatments from being fully implemented and realized. The role that health insurance and provider billing issues play in the creation or exacerbation of financial toxicity is discussed below.

Cancer Legal Care's ICARE Program – Tackling Financial Toxicity by Resolving Health Insurance and Provider Billing Issues

Cancer Legal Care's ICARE program (Insurance Claim Advocacy and REsolution) resolves health insurance and provider billing issues on behalf of Minnesota cancer patients. ICARE was created out of the growing need for Minnesota cancer patients to address insurance and provider billing issues that affect their care. The ICARE program provides the legal expertise, time, and resources that oncology providers simply do not, and should not be expected, to have.

ICARE staff is comprised of an attorney with experience consulting and representing healthcare provider systems in reimbursement actions, a nurse-attorney with a background working in a blood and bone marrow transplant unit, a former health insurance executive, and a nurse advocate with experience in administrative patient advocacy. The program also utilizes four volunteer attorneys from the insurance industry, big firm, and solo/small practice with experience in ERISA and insurance coverage issues. The volunteer attorneys serve as subject matter experts in complex matters and take some matters on pro bono.

Of the 91 ICARE matters ICARE has worked on and closed from October 2019 through May 2023, 95.6 percent have resulted in a successful outcome for our clients. Success includes:

- billing issues being corrected;
- denials overturned;
- insurance coverage being reinstated;
- claims properly processed; and
- consultations with an ICARE attorney that resolves the issue they are facing

For 52 of these clients[7] (representing 47 percent of ICARE cases), success included protecting or recovering money for the client, totaling $3,462,048.20 collectively; $66,577.85 on average for each client, with a range from $135 to $565,000. These monetary figures primarily represent[8] the

[7] Three of these clients have two or more ICARE cases.

[8] 10 percent of this monetary recovery comes from other insurance-related matters such as private life, long term disability, and short term disability insurances. Providing assistance to patients experiencing these other types of insurance issues naturally fits within the ICARE program model because of the direct link between these insurance benefits and the financial stability of a cancer patient as well as the interplay between the specific insurance issues and the cancer patient's health condition.

cost of treatments that our clients were having to forgo entirely or pay for out of pocket due to an insurance issue, and/or amounts that our clients' providers were incorrectly billing to them.

Cancer Legal Care's goal is to reduce the financial toxicity experienced by Minnesota cancer patients. For this reason, we do not charge our clients for ICARE services. A fee for these legal services would create yet another barrier to patients' access to care and compound the financial strain already caused by their insurance or billing issue. Cancer Legal Care serves any resident of Minnesota who is affected by cancer. Accordingly, the ICARE program is available to anyone living anywhere in Minnesota, with any cancer. Furthermore, we do not limit ICARE services based on income or assets because with cancer's high cost of care, a single insurance denial can have a profoundly negative impact on the financial well-being of a patient and their family regardless of socioeconomic status.

Ethan's story illustrates why Cancer Legal Care does not charge clients for ICARE services. Ethan is a pediatric cancer patient who needed a specific type of chemotherapy that would not damage his lungs. However, his insurance denied coverage for the medication, leaving Ethan's family to figure out how to pay out of pocket for at least $165,000 worth of treatment. ICARE staff dedicated more than 60 hours over the course of a week and a half to prepare a successful appeal to Ethan's insurance. Using average private attorney hourly rates in the Twin Cities ,this work represents $21,000-$30,000 in legal fees had it been performed by a private attorney in the Twin Cities with the same level of expertise as the ICARE program staff.

Additionally, provider financial assistance policies do not adequately safeguard against these problems. First, financial assistance eligibility thresholds set by Minnesota providers are often set very low at 200-400 percent of the Federal Poverty Guidelines (FPG). As a result, not all patients qualify for financial assistance yet would face extreme difficulty paying a full provider bill, especially those relating to cancer care. Moreover, providers are not generally required by law, with the exception of The Emergency Medical Treatment and Labor Act (EMTALA), to treat a patient if the provider knows the patient does not have insurance or may otherwise have difficulty paying their bill.

The vast majority of families, especially those facing the financial toxicity of cancer, could not afford the type of legal services provided by ICARE and do not have an adequate safety net to guard against financial ruin if they are unable to resolve an insurance or billing issue. Without access to free, specialized legal care that is available to everyone, Minnesota cancer patients and their families- *regardless of income*- are left with four choices:

- navigate a very complex and specialized appeal process alone without expertise;
- hire a private attorney to navigate it for them;
- pay an impossibly large bill out of pocket; or
- go without necessary and often life-saving treatment.

Barriers to Care: Pre-Service Issues

22 percent of ICARE's cases involve health insurance issues that occur prior to the patient receiving services. These issues create a barrier to care for Minnesota cancer patients because the

patient either cannot receive the service or medication at all or must pay out of pocket in order to receive the service or medication.

Coverage Cancellations

The first type of health insurance issue that creates a barrier to care is coverage cancellations. This occurs when an insurance company cancels a patient's existing health insurance coverage usually for administrative reasons, for example, issues with receipt of premium payments or a conflict between current insurance coverage and new Medicare eligibility.

Six percent[9] of ICARE's cases are related to plan cancellations. Plan cancellations create a barrier to care because until coverage is restored, the patient cannot access any care without incurring an obligation to pay the entire provider bill out of pocket. In order to restore coverage, the patient must:

- dispute the coverage cancellation; and/or
- obtain temporary insurance coverage (which is difficult for most cancer patients because such plans are generally not governed by the Affordable Care Act and many include pre-existing condition exclusions or are otherwise not comprehensive coverage); and/or
- wait for the next insurance open enrollment period, which could be months away. The options to obtain comprehensive insurance coverage require time, yet cancer patients do not often have the luxury of time to forgo medical visits.

ICARE's client, "Kyle," experienced this issue. Kyle's health insurance coverage was cancelled due to administrative issues with premium payments that should have been deducted from Kyle's bank account by the insurance company through autopay. There was a miscommunication in providing Kyle's bank routing information to the insurance company, which prevented premium payments from being withdrawn from Kyle's bank account. When premium payments were not withdrawn as expected, Kyle was not aware of the issue and the insurance company did not contact Kyle to verify whether they had the correct routing information. Instead, the insurance company mailed notices to Kyle about the missing premium payments, but Kyle was out of state for an extended time and the mail was not forwarded to him before the insurance company cancelled his coverage entirely. Without his health insurance coverage, Kyle had no other option but to wait over six months for the insurance open enrollment period and the start of the new year before he could have health insurance coverage in effect. He was experiencing significant health issues, but felt he could not afford to seek care because he did not have health insurance coverage. As a result, he avoided treatment despite experiencing severe and prolonged illness.

After contacting the plan's broker and various insurance company departments to discuss legal requirements of payment grace periods and the plan's role in the payment issues, ICARE had the issue escalated for review. The insurance company's special investigations unit reinstated coverage retroactively to the erroneous cancellation date. This reinstatement allowed Kyle to finally seek medical care, knowing that he would have insurance's help to cover the bills.

[9] ICARE figures, 01/2019-05/2023

The words of Kyle's wife encapsulate the need for and effect of the type of free legal care that ICARE provides: *"I don't know where we'd be today without your assistance getting insurance reinstated. The work you do saves lives…[Kyle] had ran out of hope. We will be forever grateful for the work you did get health insurance back up and running. Medical attention was urgently needed and [being able to go to the doctor] has stopped the [severe illness]."*

Prior Authorization Denials

The second type of health insurance issue that creates a barrier to care is prior authorization denials. This occurs where an insurance company determines that it will not cover a medical service or medication before the patient obtains the service or medication. Prior authorization denials can be made for a variety of reasons including lack of medical necessity, investigational use versus accepted standards of care, plan limitations, and plan exclusions.

13 percent of ICARE cases involve a prior authorization denial. These issues result in effectively the same outcomes as coverage cancellations since a prior authorization denial effectively means that the patient will not have insurance coverage for a service or medication because the insurance plan has determined that coverage does not apply to the service or medication. The cost of cancer treatments can be so expensive that most families cannot afford to pay for treatment out of pocket. Even if a family is able to pay out pocket, it is nonetheless a substantial impact to their financial stability, adding to the financial toxicity that cancer patients overwhelmingly face. As a result, prior authorization denials can –and far too often do–cause a cancer patient to forgo or delay life-saving or life-extending treatment.

ICARE's client "Jackie" stopped receiving her life-saving medication infusions after her insurance started to deny prior authorizations for it, claiming that the medication was not medically necessary. The high cost of the medication meant that it would be impossible for Jackie to afford it without insurance. Without this medication, Jackie's health was set to deteriorate over time, likely leading to her death. ICARE successfully appealed to insurance on her behalf with an argument proving that the medication was medically necessary. This resulted in coverage approval for the medication at a value of at least $565,000 for infusions received over the course of 14 months. With this coverage approval, Jackie was able to resume taking the vital medication to maintain her health.

ICARE's appeal required over 35 hours of legal work and involved research into the insurance plan language, insurance company's medical policy, and medical studies. Jackie's experience highlights the difficulty many cancer patients would have in advocating for themselves. Arguing the medical necessity of treatment requires experienced medical knowledge as well as a significant amount of time, energy, and resources that many cancer patients simply do not have. As Jackie said: *"I'm a fighter but I was getting discouraged. You came along and supported me and led the way."*

Delays in Prior Authorization or Appeal Processing

The third type of health insurance issue that creates a barrier to care are delays in prior authorization or appeal processing. This occurs when a service or medication requires prior authorization by the health insurance company, but there is an issue, usually administrative, that prevents the prior authorization from being fully or timely processed. This situation also happens

when there is an issue preventing a pre-service appeal from being processed at all or processed on an expedited basis. This may happen, for example, if there is an error during the transmission of the prior authorization or appeal from the health care provider to the insurance company, or if the insurance company does not flag an urgent prior authorization or appeal to be processed on an expedited basis. As a result, the prior authorization or appeal does not get approved or denied-it simply is not processed at all or is not processed in a timely fashion.

2 percent of ICARE cases involve a delay in prior authorization or appeal processing. This type of issue prevents a patient from being able to obtain the service or medication because the service or medication cannot be provided with the assurance of insurance coverage without the prior authorization or appeal determination.

ICARE's client "Leo" experienced a delay in both a pre-service appeal and prior authorization request, leading to a significant setback in his treatment progress. Leo was being treated for a very aggressive liver cancer. He completed a series of chemotherapy treatments and due to the success of that treatment, his doctor recommended a specialized and targeted radiation treatment to attempt to fully irradicate the tumor. Unfortunately, his health insurance denied the prior authorization request for the radiation. Leo's provider appealed the denial, but although this was an urgent matter due to the aggressive nature of Leo's tumor, the insurance company did not process the appeal on an expedited basis. The provider was successful in overturning the denial, but as a result of the delay in the appeal process, the insurance company took two months to determine the appeal rather than five days as required under the plan's expedited protocol. During those two months, Leo's tumor grew and spread, requiring him to undergo another round of chemotherapy to re-shrink the tumors before the specialized radiation could proceed. Later, when the second round of chemotherapy was finished and it was time for the radiation, Leo's insurance company delayed processing the renewed prior authorization request. The insurance company scheduled the prior authorization to be determined in approximately 14 days, rather than 72 hours required under the plan's expedited protocol.

ICARE made numerous phone calls to the insurance company over the course of two days, navigating through various service departments and eventually reached a representative with the authority to schedule the prior authorization request to be reviewed on an expedited basis. Insurance approved the radiation the next day. Leo's treatment had already been significantly delayed, but ICARE's involvement ensured that it was not delayed any further.

Leo's case illustrates how a patient's treatment plan is wholly uprooted not only by a health insurance denial but also by administrative processing issues. This example also highlights the reality that while oncology providers have the medical knowledge necessary to overcome a medical necessity denial, the mechanics and administrative processes relating to appeals and prior authorizations vary greatly from one health plan to another and are governed by language in plan documents that physicians often do not have access to or do not have adequate time to review. As a result, it is an impossible task for providers to be familiar with varying plan provisions to ensure that any one insurance company processes prior authorizations and appeals correctly. A lawyer on the cancer care team with expertise and familiarity in plan language plays a key role addressing and resolving these issues in a timely and effective manner.

Insurance System Errors Regarding Benefit Cost Sharing

A fourth barrier to care are insurance system errors that produce incorrect information regarding patient cost sharing amounts. An example of how this occurs is when the insurance company's automated claim processing system assigns an incorrect cost sharing amount to a type of service or medication. This can have the effect of assigning a much higher out of pocket cost to a patient for a particular service or medication than the patient should actually be responsible for. When this issue causes a patient to be assigned a very large out of pocket cost, the patient may not be able to afford the service or medication, or may struggle to afford it, adding to their financial toxicity and/or causing them to forgo the service or treatment. One percent of ICARE cases involve this issue, but as the example below illustrates, this type of issue tends to affect a large number of patients due to the systemic nature of it.

ICARE's client "Linda" encountered this problem with her health insurance company's cost sharing formulary for her prescription cancer treatment medication. The retail cost of the medication without insurance is several thousand dollars per month, so while Linda was shopping the MNSure Marketplace during open enrollment season, she diligently researched each plan's cost sharing provisions specific to the medication. After narrowing her options down to one plan which offered coverage for the medication at a cost to her of $25 per month, she contacted the plan before enrolling and confirmed that her understanding of that cost was accurate. However, after she enrolled and attempted to fill her first prescription, she was told that her out of pocket cost would be significantly higher– at least $1,000 each month. Because she could not afford this cost, Linda was forced to find an alternative way to obtain the medication and thankfully was able to obtain it for $40 through a discount pharmacy company. However, Linda was still paying the highest level of premium for the health plan in exchange for the expectation that her cost for the medication would be $25 per month. She did not feel that it was right that she was not receiving that benefit from her health plan as expected. ICARE got involved and contacted the insurance company's leadership team and provided a detailed account of the issue, demanding that insurance honor the $25 cost as they previously confirmed to Linda.

Within two weeks of ICARE's contact to the insurance company, the insurance company located an error within their claim processing system that caused incorrect cost sharing amounts to be applied to all patients taking the same medication. Not only was Linda then able to obtain her medication for $25 per month out of pocket as expected, but as a result of the insurance company's commitment to fix this systemic problem, every other patient who experienced the same incorrect cost mistake was identified and had their previous claims corrected and future claims processed at the correct cost amount.

Barriers to Care: Post-Service Issues

48 percent of ICARE's cases involve health insurance or provider billing issues that occur after the patient has received services. In these cases, a service or medication was already provided to the patient, but because of a provider billing error or health insurance denial, the patient was assigned financial responsibility for charges that the patient might not otherwise have owed. This creates a barrier to care for Minnesota cancer patients as the resulting medical debt oftentimes has a chilling effect on a patient's ability or willingness to continue with their treatment or seek additional care because they are worried about not only incurring additional debt, but paying the

current debt as well. Additionally, as reported in recent news articles, some health care system financial departments have a practice of turning away patients who have unpaid medical debt balances,[10] which adds an additional barrier to patients' ability to receive needed care.

Post-Service Insurance Denials

44 percent of ICARE cases involve a post-service insurance denial. The reasons for these denials vary greatly but include: the service provided was deemed not to be medically necessary, a required prior authorization was not timely obtained, the service was provided by an out of network physician or facility, or two health plans disagreed over which should be the primary and secondary payor.

ICARE's client "Harry" received a bill for almost $160,000 after his cancer-related hospitalization. Harry was hospitalized on the last day of his coverage under Health Plan 1 and the remainder of his hospitalization occurred during his coverage under Plan 2. Adding to the confusion regarding start and end dates of insurance coverage, Harry's hospitalization occurred during a leap year and began on February 29. After Plan 1 paid for the first day of hospitalization, Plan 2 denied coverage for all remaining days of hospitalization, claiming that Plan 1 was the responsible payor. After the provider tried unsuccessfully for almost a year to have either plan pay the denied charges, Harry received the bill. He knew that his insurance should have paid it, so he contacted ICARE.

ICARE used each plan's policy language to determine which plan was responsible for payment and contacted the provider and the health plan management and executive teams to coordinate each plan's payment obligations. Within two months, Harry's hospital bill was paid in full by the appropriate insurance company. If Harry had been required to pay the bill, he would have found himself as a financial toxicity statistic: his family would have experienced significant financial distress and would have struggled to pay their basic needs and costs of living, especially given that Harry and his wife were down to a single income to support themselves and their three minor children.

Provider Billing Errors

Four percent of ICARE cases involve a provider billing error. These typically happen when the provider incorrectly bills charges to a patient that should not be the patient's responsibility or when the provider's claim to insurance contains an error and results in an insurance denial. These issues not only add to a patient's financial strain, but also to their mental stress when they are told that they are obligated to pay for charges that they should not owe.

ICARE's client "Angela" had received a couple bills from her provider for routine lab services that had historically been paid in full by her insurance. While these bills totaled less than $500, Angela was on a fixed income. She did not have room in her budget to pay these unexpected bills without having to forgo other costs of living such as rent, food, or the continuation of her cancer treatment. Because her insurance historically paid for these services in full, Angela knew that something was wrong and contacted ICARE for help.

[10] Kilff S, Silver-Greenberg J. This Nonprofit Health System Cuts Off Patients with Medical Debt. New York Times. June 1, 2023. Olson J. Minnesota Woman with Unpaid Bills Will Lose Doctors After She Gives Birth. Star Tribune. June 12, 2023.

ICARE reviewed the billing records and contacted the insurance company. ICARE learned that a billing error– a missing "modifier" in the billing code– caused insurance to deny the claim, which was then billed to Angela in full by the provider. ICARE obtained the correct "modifier" and got the provider billing office to submit corrected claims. This resulted in the claims being paid in full by insurance with no remaining balance assigned as Angela's obligation to pay.

Providers will not usually submit an appeal to insurance or correct a claim if the amount of the claim balance is under a certain threshold such as $2,000. However, Angela's experience highlights a reality for many cancer patients: even a relatively small bill has a profound negative impact on their financial well-being. Without access to free legal care to correct these types of billing error, patients with very limited financial resources are left to make difficult financial decisions often at the detriment to their health.

Conclusion

As our clients' experiences show, health insurance and provider billing issues are often complex, difficult to navigate, energy- and resource-consuming, and pose serious risks to the financial and physical well-being of Minnesota cancer patients. These issues are too common. Until these issues no longer occur, access to free, specialized, and timely legal care is tantamount to Minnesota cancer patients' ability to receive life-saving medical care.

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