

The Cost Burden: How the Cancer Community Organizes Against High Medication Costs

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

Current cancer treatment options leave room for exploration and improvement. In the United States, the number of people living with cancer in 2016 increased to 15.5 million compared to only 3 million in 1971. Future predictions expect that 20.3 million Americans will be living with cancer by 2026 (Mayer et al., 2017). Due to the inherent complexity of cancer signaling pathways, lack of a complete scientific understanding of these pathways, and vast range of cancer types, widespread treatments that are effective and accessible do not exist. For most cancers, conventional cancer treatments may extend life duration but do not improve the quality of life. (Fox Chase Medical Center, 2019). Therefore, further research and action within the field of cancer therapeutics needs to take place if there is any hope of moving towards progress within the field.

To develop more effective and accessible cancer treatments, researchers need a better understanding of cancer signaling and networking. The goal of the associated Capstone project was to better understand signaling pathways involved in cancer development, specifically mechanisms associated with colorectal cancer. However, the goal of this research paper is to address the larger social implications surrounding cancer treatments. Even though the technical components involved in cancer treatments are vital for progression of the field, the financial toll of cancer treatment is commonly overlooked, yet is an essential component that needs to be considered. According to a 2011 forecast, the costs of cancer treatments were expected to rise 27 percent by 2020 (Mariotto et al., 2011). The expense of treatment often burdens cancer patients and their families; in response, they and their allies organize to demand less expensive care through multifaceted groups that oftentimes reach success through media platforms. Therefore, the goal of this research paper is to determine the validity of this hypothesis through exploration

of the question: How has the cancer community organized in response to the burden of high cancer medication costs?

Literature Review

Researchers have investigated the impact of cancer costs on organized responses. Rowland & Bellizzi (2014) investigated the importance of post-treatment programs, such as financial assistance, in the rehabilitation of cancer patients. Due to the high costs of medication and the toll of treatment on financial resources, organized rehabilitation is extremely valuable and impactful to cancer patients and family members (Rowland & Bellizzi, 2014). Additionally, Gilligan (2018) investigated the impact of movements towards lowering the costs of cancer medication and the associated financial benefits. High costs of cancer medications cause cancer patients and family members to more readily respond by depleting life savings, taking out second mortgages on houses, or selling other property items. However, other cancer patients may apply for Medicaid or resort to seeking aid from other financial assistance programs or advocacy groups (Gilligan, 2018). Kolker (2004) examined previous health social movements and the impact of cultural and social factors on funded activism. Specifically, the organized movements of breast cancer activists in the early 1990s provided an example of organized groups, such as cancer patients, family members, and advocacy groups, gaining ground on increased federal funding towards healthcare expenses and alleviation of high treatment costs (Kolker, 2004). These various studies provide relevant information for gaining further insight into the complexity of high cancer medication costs and the impact of organized responses to such costs.

Even though previous researchers have explored patient and familial responses to the high costs of cancer treatments, additional research is necessary to fully understand the diversity and range of organized responses. One area requiring further investigation is the impact of recent

technological advances such as social media on organized movements against high costs. The potential of connecting cancer patients and family members impacted by high medication costs is much higher now than a decade ago, which may have a high impact on organized responses (Kolker, 2004). Additionally, the intersection of various participant groups in organized responses, such as patient advocacy groups and family members, requires further exploration and investigation.

Previous research is relatively one-sided and does not necessarily address the overlap of participant groups and conjoined efforts against high cancer medication costs (Rowland & Bellizzi, 2014). The cancer community may be defined as a more widespread collective that consists not only of patients and their families, but also other participants such as physicians and policy advocates. Therefore, in order to effectively understand organized responses against high medication costs, the interconnectedness of the various involved participants should thoroughly be explored. Understanding modern and combined participant responses may provide insight into the effectiveness of efforts across participant groups, areas of improvement necessary to successfully achieve participant agendas, and the greater socioeconomic impact of such organized efforts.

Methodology

The methodology surrounding this research paper involves the utilization of multiple databases and search engines in order to gather both primary and secondary resources for analysis. Primary sources include resources such as newspaper articles and ensure a well-rounded perspective of information is gained. Secondary sources such as websites of advocacy organizations provide an additional avenue to obtain reliable information for analysis. Initial information obtained through databases such as *Web of Science* will be utilized to establish a

base of the various participant groups that comprise the cancer community. From there, additional primary and secondary sources will be used to further explore and discuss the interconnectedness of the cancer community with regards to organized action against high medication costs. Throughout this discussion, various sociotechnical components and ethical considerations will be highlighted such as inequities in care access. This will provide a more robust understanding of the various factors that impact organized responses within the cancer community against high medication costs.

Analysis

The Cost Burden

The United States healthcare system makes it difficult to access quality care at an affordable cost. Healthcare coverage within the United States does not follow a universal coverage model like those in other developed countries. Instead, the U.S. healthcare system revolves around a non-uniform hybrid system that includes a combination of coverage provided to individuals through private businesses, private funds, the federal government, and state and local governments (Barrows, 2020). This lack of uniformity perpetuates economic barriers for patients in need of medical care, while also reinforcing already existent hardships within the medical community. Therefore, not only do cancer patients face the physical and emotional strain of possibly lengthy and painful cancer treatment options, but they also face the difficulties associated with affording such treatment.

The high costs of cancer medication presents a burden to cancer patients and families striving to balance receiving needed care with the financial ramifications. Over the last twenty years, the costs of cancer medications have increased over ten-fold (Kantarjian & Rajkumar, 2015). This places financial hardships on cancer patients, especially those that do not have the

means to cover out-of-pocket expenses (Abelson, 2014). Furthermore, this creates a financial barrier for patients that need life-saving care yet simply cannot afford it. Although the high costs of cancer medication are known throughout the healthcare community, the financial burden of cancer treatment remains unchanged (Siddiqui & Rajkumar, 2012; Venkat et al., 2012). Efforts to combat such high costs have caused organized groups to form to advocate against high costs and inadequate financial coverage. In response to the high costs of cancer medication, cancer patients and their families work towards changing the coverage system of cancer treatments (Gilligan et al., 2018; Kolker, 2004).

Advocacy Groups

Oftentimes cancer patients become “victims of their own success” since successful treatment means having to also live through the financial obligations incurred through treatment (Moore, 2018). Not only have cancer patients become involved in the fight for affordable care, but their family members have also united to change coverage options for cancer patients (Kandarian, 2014). Families can become involved in cancer finances and “struggle to stay afloat” with managing finances, loved ones, and other responsibilities (Sainato, 2019). In an attempt to combat high medication costs associated with cancer treatments, patients and their families most often initially seek support through joining or forming advocacy groups that bring awareness to the financial burden of cancer treatment.

As a result of the growing costs of cancer medications, various advocacy groups have formed to assist with the financial components involved in cancer treatment. The Cancer Support Community, the largest non-profit cancer support advocacy group, is a participant focused on ensuring the best possible cancer care and connecting cancer patients with resources such as financial support (Fontana, 2020). The Cancer Support Community recognizes “cancer patients,

in particular, who are in treatment are in a vulnerable category” and “provides \$50 million in free support and navigation services each year to individuals affected by cancer” to alleviate the financial burden associated with cancer medication (Fontana, 2020; FreedomPay, 2019).

Additionally, the National Patient Advocate Foundation focuses to “promote access to affordable, quality health care for people with chronic, debilitating or life-threatening illnesses” such as cancer (Montana State Oncology Society, n.d.). Their services include items such as “Cost of Care Conversations” which are meant to help patients and their families navigate the financial components of seeking cancer treatment (National Patient Advocate Foundation, 2020).

Other advocacy groups such as the Association of Community Cancer Centers (ACCC) have been essential in providing education and resources to cancer patients and families. The ACCC has developed a variety of workshops and tools to assist with financial advocacy and addressing financial toxicity associated with high cancer medication costs. Specifically, the ACCC Financial Advocacy Boot Camp is aimed at providing online courses and professional advice to support cancer patients. Additionally, they recently provided resources to navigate financials in light of COVID-19 (Association of Community Cancer Centers, n.d.).

Petitions and Protests

In addition to the formation and growth of advocacy groups organized to combat high cancer medication costs, petitions and protests are increasing from the cancer community. Within the age of social media platforms and the Internet, petitions for change are much more accessible and doable. For example, on change.org, a petition with over 38,000 supporters was submitted to the Secretary of Health and Human Services advocating for the following actions: (1) the importation of cancer drugs across borders for patient use, (2) allowing Medicare to negotiate drug prices through the removal of current legal restrictions, (3) enacting new federal legislation

preventing pharmaceutical companies from delaying access to generic drugs, and (4) specific actions that would provide financial relief to cancer patients (“Sign the Petition,” n.d.).

This type of action is a powerful method for reaching a wider audience by drawing attention and awareness to the trends in increased financial burdens. Twenty years ago, such initiatives would not have been feasible due to the logistical challenges associated with coordinating such widespread collaboration. However, the increased usage of media platforms such as Twitter and Facebook allow for such collaboration to take place. Additionally, the use of petitions has provided the means for diverse cancer community members to become actively involved in the fight against high medication costs and its availability.

In addition to petitions, the action of protesting has been another means of organizing other players in the cancer community. Physicians for example have become more outspoken against high medication costs (Pollack, 2013). The actions of physicians at Memorial Sloan Kettering Cancer Center demonstrate the impact of successful protests against high medication costs (Grisham, 2012). In 2012, this group of physicians refused to use a newly released colorectal cancer drug, Zaltrap, due to it being twice as expensive as another drug on the market without yielding better results. This group of physicians went one step further by publicizing the matter through a New York Times Op-Ed article (Pollack, 2013). As a result, the makers of Zaltrip decided to cut the price of the drug in half (Grisham, 2012; Pollack, 2013).

Other protests have also gathered widespread attention surrounding the financial limitations of cancer treatments. A July 2020 article discussed the impact of 118 oncologists from top hospitals across from the United States voicing their frustrations with the high costs of cancer drugs (Healthcare.org, 2020). This group “drafted a prescription for reducing the high cost of cancer drugs and voiced support for a patient-based grassroots movement demanding

action (Healthcare.org, 2020).” Their suggestions were submitted to the Mayo Clinic Journal and included demands such as “passing legislation to prevent drug companies from delaying access to generic drugs” in hopes of providing more affordable treatment options (Tefferi et al., 2015) Taken together, these actions should get the attention of elected officials and pharmaceutical companies.

Legislative Efforts

In addition to advocacy, petitions, and protests, the cancer community has also used organized efforts to help pass new legislation to decrease costs. Past legislation has contributed to the increasing financial burden of cancer treatment. For example, the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 prohibits direct negotiations of drug prices with manufacturers and instead uses local contractors. Additionally, other legislation exists that “prevents Medicare from categorizing cancer drugs with related chemical structures and indications from being interchangeable, thereby eliminating competition in the market for an indication (Siddiqui & Rajkumar, 2012).” Without the allowance of any other competition, prices increase to much higher, unaffordable rates. This places Medicare in the position of a “price taker” rather than negotiator, which contributes to the high costs of cancer medications (Siddiqui & Rajkumar, 2012).

However, more recently organized efforts through additional legislation have been initiated to address pricing issues associated with previous legislation such as the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Siddiqui & Rajkumar, 2012). This past January, the Elijah E. Cummings Lower Drug Costs Now Act was passed, which has increased the “number of drugs subject to price negotiation (“New Legislation”, 2020).” Successful enactment of this bill will allow a cap to be put into effect for “out-of-pocket

prescription costs for Medicare enrollees” for the first time in history (Bunis, 2019).

Additionally, efforts have been made to revise the Prescription Drug Pricing Reduction Act of 2019, which supports maintaining Medicare Part B and D inflation rebates (“New Legislation”, 2020).

Other actions with regards to legislation have taken a more focused approach, especially within the area of lung cancer. Representative Brendan Boyle introduced the Katherine's Lung Cancer Early Detection and Survival Act of 2021 in January of 2021. This bill would require “private health insurance plans to cover, without cost sharing, screenings for the detection of lung cancer for individuals 40 years of age or older without regard to such individuals’ smoking history (National Cancer Institute, n.d.)” Another piece of legislation includes the Lung Cancer Screening Registry and Quality Improvement Act of 2021, which aims at providing grants to assist in establishing free registries and supporting the development of quality measures for lung cancer screenings (National Cancer Institute, n.d.). Both of these legislative endeavors contribute to the ongoing fight towards lowering cancer treatment costs and have gained support through the collaborative efforts of legislators with other cancer community members and usage of media to raise awareness. These are a few of the successful, organized efforts from the cancer community that have led to change within the price game for cancer treatments.

Conclusions

Overall, the financial burden associated with cancer can at times be more than the physical and emotional toll of cancer treatment. Not only does an individual that has been faced with a cancer diagnosis have to come to terms with the state of their health, but also they now then have to ask the difficult question of whether or not to even pursue action or to pursue a less quality plan of action due to financial limitations. In response to high cancer medication costs,

multiple members of the cancer community have prepared organized efforts in order to raise awareness and combat these high costs. These efforts have taken multiple forms that include advocacy groups, protests, petitions, and legislation. Additionally, analysis shows that some of the more successful movements not only included the involvement of media platforms to advance the agenda of the cancer community, but also relied upon the multidisciplinary nature and collaboration of the various participants within the cancer community. Overall, successful organized efforts from the cancer community against high cancer medication costs have been made possible through the formation of diverse, multidisciplinary groups that utilize various media platforms. Moving forward, additional action needs to be taken to decrease the extraordinarily high costs of cancer medications. Organized efforts up until this point have sparked the movement towards lowering access to care, but additional actions will contribute to longer-term and more extreme changes in the costs of such medications. With the increasing prevalence of social media and a virtual landscape, these organized efforts will have the opportunity to become larger and more widespread.

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