

Cancer Survivorship Clinics and the Financial Burden of Cancer on Patients

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Abstract

With rising costs associated with cancer care, a multidisciplinary cancer survivorship clinic approach becomes increasingly more important for optimal patient care. This essay aims to evaluate cancer survivorship clinic's effectiveness with patient satisfaction and outcomes while also addressing factors contributing to cancer patient's financial toxicity. Financial toxicity is used to describe the devastating consequences financially on the patient from rising cancer costs. This essay evaluates recent cancer survivorship research regarding effectiveness, satisfaction, and outcomes. Also, this essay evaluates cancer financial toxicity research regarding prevalence, risk factors, and the U.S. healthcare system impact. Cancer patients face much more than their cancer diagnosis. Cancer patients are faced with financial, psychosocial, and logistical challenges while battling cancer. Patient satisfaction and outcomes are greatly improved when treated in a multidisciplinary cancer clinic. Financial toxicity is a devastating consequence of cancer that many patients face. Factors such as increasing drug prices, loss of employment and limited health insurance benefits, and baseline economic status contribute to patient's battle with financial toxicity. Financial toxicity can be managed better when a patient is treated in a multidisciplinary cancer clinic due to a more patient-centered approach. Implementation of cancer survivorship clinics can positively impact both patients and providers. Patients can receive their cancer care in

one setting while improving their quality of life through decreased costs and fewer appointments. Providers are positively impacted by more effectively managing and addressing all aspects of a cancer patients' diagnosis. In public health, this is significant because cancer survivorship clinics have shown to positively impact cancer patient's treatment satisfaction, quality of life, and outcomes.

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1.0 Introduction

Cancer can be devastating to those impacted and the ramifications from cancer treatment can be equally as bad. Cancer is extremely prevalent, as seen by the 2020 National Cancer Institute report, “An estimated 1,806,590 new cases of cancer will be diagnosed in the United States and 606,520 people will die from the disease” (“Cancer Statistics”, 2020). While a significant number of people will develop cancer, many will become cancer survivors after undergoing treatment. According to the National Cancer Institute, “As of January 2019, there were an estimated 16.9 million cancer survivors in the United States. The number of cancer survivors is projected to increase to 22.3 million by 2030” (“Cancer Statistics”, 2020). Surviving cancer is an impressive feat, but post-cancer care can become burdensome financially, psychologically, and socially. Those battling cancer may not consider what their life will look like after they struggle with cancer.

Financial toxicity describes how patients struggle with finances due to all the out-of-pocket costs associated with treatment. With cancer being one of the most expensive medical conditions to treat in the United States of America, some of these expenses fall onto the patient after hitting their insurance maximums. Cancer survivors struggle financially with some survivors spending more than 20% of their annual income on medical care (“Financial toxicity (financial distress) and cancer treatment (pdq®)–patient version”, 2019). Various models of cancer care are seen throughout the US, but some are more suitable for combatting the consequences of financial toxicity among cancer survivors. Rising costs, additional stress, and decreased quality of life negatively contribute to a cancer patient’s journey.

2.0 Literature Review

Governmental agencies, Wiley Online Library, and cancer-focused research were the primary sources of information for the following text. The keywords used for many online searches were “Financial Toxicity” OR “Multidisciplinary Cancer Clinic” OR “Cancer Survivorship”. A review of peer-reviewed papers in the Medline database was analyzed to examine a multidisciplinary team approach. After an initial review, many studies and webpages were disregarded because they were unrelated or duplicates of information.

3.0 Overview of Cancer Survivorship and Clinics

Cancer survivorship is defined as, “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition” (“Survivorship Care”). While a patient endures cancer, so do their family, friends, and caregivers. The goals of cancer treatment are to “cure” cancer, if possible; prolong survival; and provide the best possible quality of life during and after treatment (“Cancer Treatment & Survivorship Facts & Figures 2019-2021”). There are a variety of cancer survivorship care programs across the U.S., but all have the common mission of providing high-quality treatment to cancer survivors. One approach is a multidisciplinary cancer survivorship clinic in which patients are seen during one visit by a multitude of health specialists. Navigating cancer care can be complex, but with the proper infrastructure and approach, patients can live a higher quality of life.

3.1 Challenges with Improving the Quality of Survivorship Care

Many potential challenges are faced by cancer survivors. Survivorship care encompasses a range of issues faced by survivors including physical, mental, and social components of the cancer experience (Gilbert et al., 2008). With the aging of the population, an increase in the number of individuals diagnosed with cancer is an inevitable consequence. Maintaining high-quality care for cancer patients becomes even more difficult with the anticipated shortage of health professionals. A report from the Association of American Medical Colleges indicates, “The United

States will face a shortage of between 54,100 and 139,000 physicians by 2033” (Boyle, 2020). Specifically concerning the oncology field, “A fifth of oncologists are nearing retirement age of 64 years or older and 15.6% of oncologists are early in their career at age 40 or below” (Cohn-Emery, 2020). The combination of an aging population and improvements in cancer survival rates puts a strain on the oncology workforce in the future. Cancer therapies and management strategies have greatly improved, which has resulted in significant advancements in survival for cancer patients over the years. Still, despite improved therapies and management strategies, cancer patients will sometimes struggle to receive high-quality care due to the increase in individuals with cancer and the decrease in the oncology workforce.

Another challenge facing the quality of survivorship care is the coordination of care between health care professionals. Patients with cancer often require the expertise of many different health professionals. Two challenges are presented when a patient needs to be seen by a multitude of specialists. The patient needs to have the flexibility, time, and money to be seen by the various health professionals. From the providers’ perspective, coordination amongst a group of health professionals is needed to maintain high-quality care throughout the survivorship care. Luckily, multidisciplinary cancer survivorship clinics allow a patient to be seen by a multitude of health care professionals during one visit. Multidisciplinary clinics (MDC) and multidisciplinary-specific clinics differ in many ways. Two ways they are different are related to volume and expertise. MDCs for all cancer types have providers with vast knowledge and see large volumes of patients. Disease-specific MDCs lack the volume, but providers have expertise on that specific cancer.

While a patient’s cancer is being treated, there is growing evidence that the psychosocial needs of the patient are unmet (Ganz, 2009). The failure of treating a patient’s psychosocial needs

can compromise the intended results of cancer care. A combination of social isolation, stress, and untreated mental health problems can contribute to cancer patients' interference with adhering to their treatment process. Depression, mental health problems, and limited financial resources contribute to the increased mortality and decreased functional status of the cancer patient (Adler, 2008). Inadequate social support can negatively impact a cancer survivor's experience. Inadequate income increases one's stress and can make everyday life more complicated when purchasing necessities such as food, medications, shelter, and transportation. For example, a cancer patients' inadequate income can complicate how they will travel to medical appointments or travel to the pharmacy for their prescriptions. With low income, transportation to these necessary medical appointments and medications becomes difficult. Fulfilling the psychosocial needs of cancer patients is a critical component for successful treatment and outcomes for those with cancer.

3.2 Patient and Provider Satisfaction with Multidisciplinary Cancer Clinics

MDCs have become increasingly more prominent in the way cancer care is delivered to patients. MDCs focus on patient-centered care while allowing a patient to be seen by multiple healthcare professionals in a single visit. This integrated team approach results in improved health outcomes for patients. As defined in integrated MDC research, "A multidisciplinary (or multimodality) clinic is defined as a group of health care professionals who have cognitive and procedural expertise in different areas of care delivery and can efficiently manage complex medical conditions" (Tyler et al., 2015). This approach to patient care enables collaboration amongst healthcare professionals to consider the best treatment options and develop an individualized approach. Navigating cancer care can be difficult, but with the implementation of

multidisciplinary clinics, patients and physicians are typically more satisfied. In a research study analyzing patient satisfaction from the implementation of a multidisciplinary cancer clinic by Intermountain Healthcare, it was found, “98% of our patients gave us an excellent rating on the overall clinic experience” (Litton et al., 2010). The overall high satisfaction of the multidisciplinary cancer clinic is a result of patients receiving convenient high-quality care that results in excellent outcomes. Also, the clinic proved to be a vital source of expertise in one location for the patient.

To examine patient satisfaction with MDCs, a study was conducted looking at Press-Ganey patient satisfaction scores. Specifically, examining patients’ responses regarding the degree to which care between doctors and other health professionals was coordinated, the overall care is given at the facility, and the likelihood of recommending the services to others. The answers to the questions were reported on a scale from one to five. One being very poor and five being very good. Also, providers were asked about their perspectives on the advantages and drawbacks of MDCs. Specifically, providers were asked, “About the efficiency of the clinics, the clinics’ value for patients, providers’ personal preferences for working in these clinics, perceptions of patient satisfaction and, in an open-ended manner, any other comments or suggestions for improving the MDCs” (“Article tools”, 2016). The results from the provider’s responses showed that more than 90% of providers enjoyed working in MDCs. 90% of providers perceived patients as appreciating the unique care provided in MDCs. Half of the providers thought the clinics did not run efficiently. Specifically, surgeons believed that MDCs were not an efficient use of their time. Surgeons did, however, believe the MDCs allowed them to deliver more comprehensive, coordinated, and appropriate care and agreed that patients appreciated the care they received due to the coordinated care approach (“Article tools”, 2016).

The results from the Press-Ganey patient satisfaction scores showed consistent and high levels of satisfaction for MDCs. The four patient-related questions analyzed were, “The degree to which the staff worked together to provide care, the level of care coordination among doctors, the overall care received at the facility, and the more global assessment of the likelihood that patients would recommend services” (“Article tools”, 2016). The patient satisfaction percentage for each question was above 93% showing high levels of satisfaction regarding MDCs. High levels of patient satisfaction come at the cost of sometimes inefficient clinics. MDCs provide patients with a coordinated assessment and treatment plan for their complex oncologic disease. Providers have recognized the value that MDCs provide to patients. Overall, patients are highly satisfied with MDCs while providers are as well but some of the benefits come at a cost of less efficient operations.

3.3 Patient Outcomes Associated with Multidisciplinary Cancer Clinics

Optimal patient care is increasingly associated with multidisciplinary teams (MDT). These MDTs include, “Core and allied members including radiologists, pathologists, surgeons, radiation and medical oncologists, oncology nurses, palliative care physicians, head and neck specialists, nuclear medicine specialist, respiratory disease physicians, gastrointestinal disease physicians and anesthesiologists” (Prades et al., 2015). In a study aiming to understand the impact of MDTs had on patient outcomes, fifty-one papers were selected for review on improved outcomes associated with multidisciplinary patient management. Of the fifty-one papers selected, two underlying principles were discovered as to why an MDT approach was best for patients. First, MDTs allowed more appropriate treatment with a preoperative review of imaging and pathology results (Prades

et al., 2015). Secondly, the MDT approach allowed the most up-to-date treatment for cancer patients. The review of peer-reviewed articles that examined multidisciplinary clinical practice and organization in cancer care showed, “MDTs resulted in better clinical and process outcomes for cancer patients, with evidence of improved survival among colorectal, head and neck, breast, oesophageal and lung cancer patients across the study period (2005-2012) (Prades et al., 2015). These results can be attributed to a reduced time from diagnosis to treatment, MDT organization, and communication with and delivery of information to patients. The collaboration amongst the multidisciplinary team evolved into a more comprehensive management approach from diagnosis to treatment and follow-up.

Head and neck cancer patients are best treated and managed using an MDT due to the complexity and diversified group of malignancies. In a study analyzing the differences in outcome and survival data of head and neck cancer patients between MDC managed care and non-MDC managed care, MDC managed care patients had significantly improved 5-year survival compared with the non-MDC managed patients (Friedland et al., 2011). MDC managed care was defined as patients working with various health specialists for an individualized treatment plan. Non-MDC managed patients were defined as those treated by individual disciplines in the same institution. When analyzing differences between MDCs versus non-MDCs, “Patients seen in the multidisciplinary clinic were significantly less likely to receive radiotherapy alone for positive nodes, significantly less likely to receive surgical treatment alone for their cancer and positive nodes” (Friedland et al., 2011). These differences can contribute to the difference in improved survival of head and neck cancer patients.

4.0 Financial Toxicity Among Cancer Survivors

Financial toxicity stems from cancer being one of the most expensive medical conditions to treat in the United States. Financial toxicity is used to describe, “How out-of-pocket costs can cause financial problems for a patient” (“Financial toxicity (financial distress) and cancer treatment (pdq®)–patient version”, 2019). Cancer patient’s out-of-pocket costs include copayments, deductibles, and coinsurance. In addition to the direct costs associated with treating cancer, indirect costs such as affecting one’s ability to work further contribute to financial hardship. Many factors contribute to the level of financial toxicity a cancer patient faces. Factors such as type of cancer, how severe it is, and how long one will receive treatment contributing to the level of financial toxicity a patient faces. Other contributing factors are one’s age, race, income, and the ability to have a job while undergoing cancer treatment and post-cancer. The type of insurance or absence of insurance affects the out-of-pocket costs a cancer patient is faced with. Overall, cancer survivors are more likely to report higher out-of-pocket spending than those that have not had cancer. In extreme examples, cancer survivors need to file for bankruptcy as indicated by cancer survivors being 2.7 times more likely to file for bankruptcy than individuals without cancer (“Financial toxicity (financial distress) and cancer treatment (pdq®)–patient version”, 2019). In addition to navigating the complexities that come with a cancer diagnosis, patients must battle significant financial hardship.

A systematic review of financial toxicity among cancer patients revealed that being female, being younger in age, having lower income at baseline, using adjuvant therapies, and having a more recent diagnosis increase one’s risk of financial toxicity (Gordon et al., 2016). Cancer drugs

significantly contribute to the financial burden patients suffer from. Despite cancer drugs being the key to survival, the price for these drugs far exceeds the amount patients have to spend. According to the US Food and Drug Administration-Approved Oral Cancer Drugs from 2016 to 2017 the cost per month of treatment can range from about \$7500 to \$25,000 monthly. With this steep price for drugs, many patients, despite being insured, reach their out-of-pocket maximum quickly. There is no sign of drug prices decreasing as indicated by a 10% increase in price or about \$8,500, per year, between 1995 to 2013 – adjusted for inflation.

Clinicians play a unique role in managing financial toxicity among cancer patients. Clinicians have expressed concern regarding the affordability of cancer drugs, “Encouraging the development and use of generics and biosimilars, transparency in drug costs, negotiation of drug prices by Medicare, as well as high-value drug development” (Carrera et al., 2018). Clinicians have been supporters for more affordable treatments for those suffering from cancer. Clinicians play a key role in not just delivering high-quality medical treatments but helping patients navigate financial difficulty short-term and long-term. The clinician is many times the link between health insurance and the cancer clinic and advocates on behalf of their patients. Additionally, clinicians can use their position and promote high-quality cancer care which involves the avoidance of low-value treatments. Clinicians are important in decreasing treatment costs and advocating on behalf of their patients.

4.1 Factors Contributing to Financial Toxicity

The direct costs of cancer treatments are not the only factors contributing to financial toxicity among cancer patients. A study of those participating in the medical expenditure panel

survey found, “Patients undergoing cancer treatment missed 22.3 more days of work per year than people without cancer treatment” (“Financial toxicity after a cancer diagnosis - it's impact & factors - triage cancer-finances-work-insurance: Triage cancer”, 2021). Of the 89,520 patients who participated, low-income women were disproportionately affected. Beyond job loss, many cancer patients used their savings to pay for medical treatments – which contributes to considerable medical debt for some. The stress and financial concern of cancer patients and their families further contribute to financial toxicity. The physical, psychological and financial impact of cancer does not end when the treatment does. Those who are post-diagnosis still report increased financial stress along with depression and anxiety.

Loss of employment for cancer patients further complicates costs as a loss of employment limits access to employer health benefits. To eliminate this problem, a recent study found that 20% of cancer survivors stay in their jobs mainly to keep their health insurance (Pietrangelo, 2020). Continuing to work while in active treatment is sometimes a challenge. From finding the time for medically necessary appointments and treatment to fulfilling other obligations, patients that are employed endure additional stress along with battling cancer. Also, employers spend significantly more for those employees who have a cancer diagnosis compared to no diagnosis. In a study analyzing costs employers face it was reported, “For the period 2002-2005, the combined total annual cost for working patients undergoing chemotherapy was approximately \$76,000 compared with approximately \$21,000 for patients not receiving chemotherapy” (Lawless, 2009). This statistic indicates the long-term issues employers face, similar to the long-term effects cancer patients face. The costs associated with cancer care are devastating for both employees and employers.

The greatest risk of being affected by financial toxicity, unsurprisingly, are low-income patients and uninsured patients. Along with low-income and no insurance, African Americans and patients requiring more intense treatments have a higher risk of financial hardship. Not only does low-income contribute to a greater chance of suffering from financial toxicity, low- and middle-income cancer patients suffer from higher cancer death rates. In a study examining death rates between incomes it was found, “ In low-income counties, the average cancer death rate in 2014 was 230 per 100,000 people, compared with 205 per 100,000 in middle-income counties and 186 per 100,000 in high-income counties” (“Factors linking disparities in cancer deaths, income”). Uninsured patients are at an increased risk of financial toxicity due to high costs not covered by a health insurer. Researchers found that before 2014, 5.7 percent of first-time cancer-diagnosed patients were uninsured. However, with the implementation of the Affordable Care Act, the percentage of first-time cancer-diagnosed patients decreased to 1.9 percent in 2014. (“ACA brought decline in new cancer patients who were uninsured, 2017”). African Americans are disproportionately affected by financial hardship related to cancer care. In a research study focused on the economic hardship of cancer survivors one year after diagnosis, approximately 68% of African Americans reported economic hardship. (Pisu et al., 2015). The disparity between white and African American economic hardship from cancer was explained by baseline economic status.

4.2 How the US Healthcare System Impacts Cost

Patients receive cancer care in the U.S. through a continuum of coordinated care. Risk assessment and prevention is typically the first step in the continuum of care for cancer patients, followed by screening and detection, diagnosis, treatment, survivorship, and end-of-life care.

Several factors affect access to care including societal, health care system, provider issues, and patient factors (Yabroff et al., 2019). Multiple breakdowns in the delivery of health care through the cancer care continuum contribute to additional testing and cost. For example, a patient's lack of follow-up on abnormal findings between the screening and detection and diagnosis stages can lead to serious consequences in the future.

Cancer care becomes challenging in the U.S. when coordination is needed across multiple insurance plans, hospitals, and practices – especially if medical records and patient data cannot be easily integrated. If medical records and patient data are not easily transferrable between facilities or providers, increased costs can occur indicated by, “Despite ongoing efforts to improve health information technology infrastructure, this lack of coordination can result in duplication of services, overuse of ineffective care, underuse of effective care, and misuse of health care services” (Yabroff et al., 2019). These inefficiencies contribute to the rising costs associated with cancer care. In addition to cost, these inefficiencies may contribute to health disparities among populations.

Disparities in care and cost in the U.S. can be contributed to the geographic location in which a patient resides. Patients that live in more rural locations lack the accessibilities to services or find them to be limited. The difference in mortality between rural areas and urban areas is growing wider due to a variety of factors including, “These patients may not be aware of the necessary screening modalities, are diagnosed at later stages, have overall worse outcomes, for many reasons have lesser interest for accrual¹ on clinical trials, and experience negative psychological and financial impacts because of time spent traveling for treatment” (Petinga, 2019). The differences in mortality are complex but the underlying issues of how the U.S. healthcare system is structured is partially at fault. One factor is the number of oncologists serving urban and

rural communities, “More than 59 million Americans (19%) live in U.S. Census- designated rural areas, meaning that there is approximately one oncologist per 100,000 rural residents, compared with five oncologists per 100,000 urban residents” (Petinga, 2019). The sizable difference in the number of oncologists leads to a lack of access for those living in rural communities.

4.3 How Multidisciplinary Clinics Mitigate Financial Toxicity

Head and neck cancer (HNC) patients need to see a wide range of specialists for optimal care. An HNC patient may need to be seen by an otolaryngologist, physical therapist, speech-language pathologist, audiologist, behavioral health specialist, dentist, dietitian, and oncology nurse. Scheduling individual appointments to be seen by each specialist can be costly. The United States has enacted policies to shift away from the traditional fee-for-service model (Tom et al., 2016). One such model is the bundled payment model, where a patient is charged a single payment for each appointment and the payment is shared among all providers who contributed to the appointment. This approach incentivizes the providers to deliver high-quality care and reduce administrative waste (Tom et al., 2016). Bundled payment model outcomes surrounding cancer care is limited, but they have generally shown decreased costs and positive outcomes. HNC costs are expensive and expected to only increase, “The cost of HNC in the United States was approximately \$3.64 billion in 2012, and the projected cost in 2020 is between \$3.79 billion and \$5.46 billion” (Tom et al., 2016). A research study determining which factors influence cost in HNC to notify the development of a bundled payment concluded, “The number of treatment modalities required is the primary driver of cost in HNC” (Tom et al., 2016). This finding indicates bundled payments would help reduce costs amongst HNC patients. This research also indicated

that patient factors, including Charlson² comorbidity index, had no significant impact on cost with this population (Tom et al., 2016).

5.0 Discussion

When analyzing previous research regarding multidisciplinary cancer survivorship clinics, it is evident the benefits these settings have on patients. With the number of patients diagnosed with cancer on the rise along with costs to treat cancer increasing, implementing more cancer survivorship clinics is increasingly important. More data and research are needed to address how cancer survivorship clinics affect every type of cancer. While researching cancer clinics and financial toxicity, it was evident how important treating the psychosocial needs of the patient is. Treating the psychosocial needs of a cancer patient can positively influence the intended results of cancer treatment. It is difficult to understand exactly to what degree treating the psychosocial needs of a cancer patient has on cancer treatment. Each cancer patient is in a unique position concerning finances, support systems, and underlying mental health conditions. Further research is needed to understand how each unintended consequence of cancer negatively impacts cancer treatment.

The challenge of managing financial toxicity was prevalent throughout all research. The multidisciplinary approach provided some relief in costs due to providers collaborating more and providing more effective care to cancer patients. One payment is typically collected when a patient visits a multidisciplinary clinic. Further research is needed to determine how to ensure this bundled payment model can be sustained for the hospital. Patient satisfaction and outcomes are positively affected by multidisciplinary clinics, but how the hospital can remain profitable while only charging one fee for multiple providers needs further evaluation.

Patients living in more rural geographic locations face additional challenges that patients living closer to a city do not face. Patients in rural communities are disproportionately affected by

the oncologist shortage. Patients in rural communities may have more difficulty accessing necessary cancer treatments and therefore negatively suffer due to delayed diagnoses, lack of awareness for cancer screening, and spend significantly more time traveling to appointments. Further investigation is needed to determine how rural communities can become more aware of cancer diagnoses and properly be diagnosed. With earlier intervention, patients can better manage their cancer diagnoses.

6.0 Conclusion

Cancer patients need to receive high-quality care while going through a traumatic time in their life. Patients face much more than their cancer diagnosis as they struggle with financial, psychosocial, and logistical difficulties as well. Untreated mental health problems and inadequate social support can further compromise effective cancer treatment. Additional stress from life's challenges can adversely affect patient treatment outcomes. Cancer patients face logistical difficulties with the number of appointments required for their care while maintaining a job and health insurance benefits. High-quality patient care can come from MDCs due to their unique approach and structure. From the healthcare provider's perspective, a combination of better cancer drugs that allow patients to live longer and a decrease in the oncology workforce put a strain on providing optimal patient care. MDCs can alleviate patient and provider stress with the adoption of patient-center care while allowing providers to better care for their patients. Besides some inefficiencies seen by surgeons in how MDCs, both patients and providers are generally more satisfied with this approach to their cancer care. MDCs ensure patient-centered care due to multiple specialists working together to deliver optimal results. Not only does the multidisciplinary approach improve patient satisfaction and outcomes, but cancer patient financial toxicity can also be managed better. Incorporating a multidisciplinary cancer clinic approach can save cancer patients every year between a bundled payment option and decrease the number of appointments. Also, indirect costs from cancer treatment can be avoided, such as not missing work or losing health insurance benefits due to not working, with MDCs. From a public health perspective, MDCs

allow patients to receive optimal care while reducing the additional stress a cancer diagnosis brings.

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