



HHS Public Access

Author manuscript

Support Care Cancer. Author manuscript; available in PMC 2020 September 25.

Published in final edited form as:

Support Care Cancer. 2019 June ; 27(6): 1969–1971. doi:10.1007/s00520-019-04703-6.

Cancer Survivorship Care Plans, Financial Toxicity, and Financial Planning: Alleviating Financial Distress among Cancer Survivors

Steven S. Coughlin, PhD, MPH^{1,2}, Lorraine T. Dean, ScD^{3,4}

¹Department of Population Health Sciences, Medical College of Georgia, Augusta University, Augusta, GA

²Research Service, Charlie Norwood Veterans Administration Medical Center, Augusta, GA

³Department of Epidemiology (primary), Department of Health Policy & Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, US

⁴Department of Oncology, Johns Hopkins School of Medicine, Baltimore, Maryland, US

Abstract

Concomitant with the increasing use of cancer care plans has been an increasing awareness of the potential for oncology care to result in long-term financial burdens and financial toxicity. Cancer survivors can benefit from information on support and resources to help them navigate the challenges after acute cancer treatment. While cancer survivorship plans could be a vehicle for patients to receive information on how to mitigate financial toxicity, cancer survivorship plans have typically not dealt with the financial impact of cancer treatment or follow-up care. Embedding information into cancer survivorship plans on how to reduce or avoid financial toxicity presents an opportunity to address a highly prevalent patient need. Patient-centered qualitative studies are needed to assess the type, format and level of detail of the information provided.

Keywords

cancer survivors; cancer survivorship care plans; costs; financial distress

Cancer survivorship care plans have been increasingly adopted in oncology [1]. The purpose of these plans, which are typically provided at the end of acute cancer therapy, is to help cancer survivors deal with the challenges associated with cancer survivorship [2].

Address for correspondence: Dr. Steven Coughlin, Department of Population Health Sciences, Medical College of Georgia, Augusta University, 1120 15th Street, Augusta, GA 30912, scoughlin@augusta.edu.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Ethical Statement

This article does not contain any studies with human participants performed by any of the authors. The authors do not have control over any full data.

Disclaimer: The views expressed in this article do not reflect the official position of the Department of Veterans Affairs or the National Institutes of Health.

Survivorship care plans summarize the patient's treatment and possible late effects of cancer treatment and provide follow-up care plans.

In addition, there has been an increasing awareness of the potential for oncology care to result in long-term financial burdens [3] and financial toxicity [4]. About 28% to 48% of cancer survivors experience financial toxicity based upon monetary measures (covering out of pocket spending and percentage of out of pocket spending to income ratios) and (depending on study design, etc.) 16% to 73% experience financial toxicity based upon subjective measures [5]. However, cancer survivorship plans have typically not dealt with the financial impact of cancer treatment or follow-up care, but the inclusion of such information should be considered.

BACKGROUND

Cancer survivors may be vulnerable to out-of-pocket expenses due to unemployment, medical debt, and diminished consumer credit [6, 7]. This is especially true for women, young patients, racial and ethnic minorities, persons who have low income or low financial literacy, and those without health insurance [3, 5]. Patients who report cancer-related financial problems or high costs are more likely to forgo or delay prescription medications, mental health care and other medical care [5, 8]. Financial distress due to financial obligations, debt, and diminished wealth may interfere with the ability of cancer patients to cope with physical symptoms and follow-up care, and lead to poorer health-related quality of life and health outcomes and greater premature mortality [5, 9]. To address the financial needs of cancer survivors, there is a need for patient resources about financial considerations and managing the costs of cancer survivorship care.

Cancer survivorship plans can address patient's needs by providing information on expected direct costs (e.g., copayments) and indirect costs (e.g., time off from work and the costs of transportation) of follow-up care, and providing resources to manage and minimize those costs. Studies have shown that the cascade of economic burden of cancer starts at diagnosis and leads to medical debt, financial declines, and appreciable out-of-pocket expenses long after the completion of acute oncology care [3, 10, 11]. This can occur due to lost productivity due to chronic adverse effects of cancer treatment, missed days from work due to illness, unemployment, and depletion of financial assets [7, 10]. Studies have shown that survivors can experience difficulty paying for medical bills and basic necessities such as utilities, mortgage, and food [11]. Patients may use retirement savings, borrow money, use credit, or mortgage their home to pay for the cost of oncology care [6, 10]. Cancer survivors' risk of bankruptcy, which has been associated with increased risk of mortality [12], is 2.5 to 5 times higher than those with no cancer history [13]. Information for cancer survivors might include information on navigating conversations with employers, engaging policies for job protection, and credit and debt management.

Such information could be provided in cancer survivorship plans, similar to the information disseminated by ASCO and CancerCare to patients just beginning or receiving primary cancer care. Leading cancer organizations such as ASCO have developed materials for cancer patients to help them manage the cost of cancer care. This includes information for

patients who are just starting cancer treatment such as questions to ask providers about costs, financial resources available to patients currently receiving cancer treatment, medication and treatment cost assistance (e.g., Partnership for Prescription assistance), help available from service organizations such as the American Cancer Society, housing assistance (e.g., Ronald McDonald House Charities), and basic information about health insurance and the Affordable Care Act [13]. In these patient resources, the focus is on acute oncology care. For example, information provided by CancerCare tells patients “Do not delay applying for benefits [e.g., Medicare and Medicaid] as it can take a long time for them to process” [14]. While these organizations are currently filling the gap for providing resources, these resources may be readily available to those who have the means to seek out the information while missing the most vulnerable, or those who have completed acute care.

Cancer survivorship plans also have the opportunity to provide information to patients at different stages of disease. Cancer survivors who have completed primary treatment often have very different financial concerns and difficulties than those of patients who are just beginning cancer treatment. For example, patients who have gone into debt or experienced diminished consumer credit would likely benefit from information about how to get out of debt or improve their credit. Patients with advanced cancer may be especially vulnerable to financial distress, due to the difficulties of generating or increasing income in the context of a debilitating disease and the high cost of targeted therapies [15]. Patients who have advanced-stage disease may also benefit from financial information that is not provided in existing patient resources about managing the cost of cancer. This might include where to access resources on financial management for end-of-life, setting up trusts, or estate planning.

Using cancer survivorship plans as a way to provide information on cost and financial resources to help with cost can also resolve a challenge that many providers cite. Several studies have suggested that medical providers do not always feel they have the appropriate information to discuss financial issues with patients [16, 17]. At institutions where cancer survivorship plans are based on a template, there could be (modifiable) language about expected costs for certain potential treatments, or adverse effects, as well as guidance on how to access institution-specific, publicly available, or other charitable assistance.

Embedding information into cancer survivorship plans on how to reduce or avoid financial toxicity presents an opportunity to address a highly prevalent patient need. Using survivorship care plans as vehicle for providing information on financial resources could help disseminate information on financial resources, reduce the likelihood of patients abandoning follow-up treatment due to cost, and reduce financial distress for cancer patients.

Acknowledgments

Dr. Dean’s effort is supported by the National Cancer Institute grant K01CA184288; the Sidney Kimmel Cancer Center grant P30CA006973; Johns Hopkins University Center for AIDS Research grant P30AI094189, and the National Institute of Mental Health grant R25MH083620.

REFERENCES

1. Hewitt M, Greenfield S, and Stovall E. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC National Academies Press, 2006.
2. Van de Poll-Franse LV, Nicolaije KAH, and Ezendam NPM. The impact of cancer survivorship care plans on patient and health care provider outcomes: a current perspective. *Acta Oncologica* 2017;56(2):134–8. [PubMed: 28084140]
3. Jagsi R, Pottow JA, Griffith KA, et al. Long-term financial burden of breast cancer: experiences of a diverse cohort of survivors identified through population-based registries. *J Clin Oncol* 2014;32:1269–76. [PubMed: 24663041]
4. Zafar SY, Abernethy AP. Financial toxicity, part I: a new name for a growing problem. *Oncology* (Williston Park, NY). 2013;27(2):80–149.
5. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin* 2018;68:153–65. [PubMed: 29338071]
6. Dean LT, Schmitz KH, Frick KD, et al. Consumer credit as a novel marker for economic burden and health after cancer in a diverse population of breast cancer survivors in the USA. *J Cancer Survivorship* 2018;12:306–15.
7. Pisu M, Azuero A, McNeese P, et al. The out of pocket cost of breast cancer survivors: a review. *J Cancer Surv* 2010;4:202–9.
8. Kent EE, Forsythe LP, Yabroff KR, et al. Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer* 2013;119:3710–17. [PubMed: 23907958]
9. Ramsey S, Blough D, Kirchoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)* 2013;32:1143–52. [PubMed: 23676531]
10. Dean LT, Moss SL, Ransome Y, et al. “It still affects our economic situation”: long-term economic burden of breast cancer and lymphedema. *Supportive Care Cancer* 2018;[online first]
11. Altice CK, Banegas MP, Tucker-Seeley RD, et al. Financial hardships experienced by cancer survivors: a systematic review. *J Natl Cancer Inst* 2017;109:djw205. [PubMed: 27754926]
12. Ramsey SD, Bansal A, Fedorenko CR, et al. Financial insolvency as a risk factor for early mortality among patients with cancer. *Journal of Clinical Oncology*. 2016; 34(9):980–986. [PubMed: 26811521]
13. Banegas MP, Guy GP Jr, de Moor JS, et al. For working-age cancer survivors, medical debt and bankruptcy create financial hardships. *Health Aff (Millwood)* 2016;35:54–61. [PubMed: 26733701]
14. Cancer.Net. Financial considerations www.cancer.net/navigating-cancer-care/financial-considerations [accessed November 5, 2018]
15. Cancer Care. Managing the cost of cancer www.cancer.care.org/publications/365-managing_the_cost_of_cancer [accessed November 5, 2018]
16. Delgado-Guay M, Ferrer J, Rieber AG, et al. Financial distress and its associations with physical and emotional symptoms and quality of life among advanced cancer patients. *The Oncologist* 2015;20:1092–8. [PubMed: 26205738]
17. Shih YC, Chien CR. A review of cost communication in oncology: Patient attitude, provider acceptance, and outcome assessment. *Cancer*. 2017;123(6):928–39. [PubMed: 27893929]
18. Nipp RD, Sonet EM, and Guy GP. Communicating the Financial Burden of Treatment With Patients. *American Society of Clinical Oncology Educational Book* (2018); 38: 524–531. [PubMed: 30231377]