

Communicating about Costs:

A qualitative analysis to understand the out-of-pocket financial burden associated with cancer care

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LIVESTRONG

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TABLE OF CONTENTS

Executive Summary.....	iii-vi
Policy Question.....	1
Introduction.....	1
Background: Cancer Care and the Underinsured.....	2
Data and Methods.....	7
Results and Discussion.....	11
Recommendations.....	23
Conclusion.....	27
Appendix.....	28
Acknowledgements.....	36
References.....	37

EXECUTIVE SUMMARY

Policy Question

In the context of health care reform, how can LIVESTRONG improve communication about the out-of-pocket costs of cancer care for its Navigation clients? Specifically, what resources could minimize the financial burden for female breast cancer patients receiving Medicare?

Recommendations

The goal of this study was two-fold: 1) develop recommendations to target LIVESTRONG's research about the practical concerns of survivorship, and 2) improve the effectiveness and impact of LIVESTRONG's navigation services. Correspondingly, my recommendations are separated into these two categories. Past research on patient-provider communication, medical decision-making, and cost-effectiveness precede this work.

All recommendations were evaluated using the criteria of minimizing implementation costs, maximizing collaboration and buy-in among stakeholders, and maximizing applicability to clients of diverse backgrounds.

A. Recommendations for Further Research

1. **Conduct market research to develop a segmented approach to assist different client groups.** OOP costs are a universal challenge. However, different types of individuals (age, gender, race, socio-economic position, insurance type, etc.) access information in different ways. These groups may have different coping strategies and varying comfort levels in discussing costs. The Medicare population in this study, for example, had limited experience using the Internet. They also did not appear to be widely connected to the larger community of cancer survivors. Although this insight is relatively simple, there is not extensive segmentation research to date on this topic.
2. **Build an infrastructure of partners, professional standards, and political support to advance the field of cancer navigation.** Since payers do not yet recognize these services for reimbursement, it will be important to demonstrate value for money and any associated cost savings for these services. Any overlap or points of collaboration with other medical providers, including nurse practitioners, social workers, and medical financial counselors, should be carefully studied.

B. Recommendations for Clinical Practice

3. **Improve tools that facilitate information sharing between patients and providers and increase ease of accessing financial assistance.** There are two

audiences for these tools: 1) direct access by patients and caregivers and 2) professional use by the cancer care team that works with patients, including social workers, financial counselors, and cancer navigators.

4. **Develop a curriculum that instructs professionals in techniques to share information on the financial impacts of cancer treatment at the clinical level.** Use LIVESTRONG Survivorship Centers of Excellence as a platform to develop targeted programs for physicians, medical professionals, and patient assistance organizations.
5. **Lobby for more accountability and transparency** about the cost of care, and consumer protection from prohibitive cost sharing, high interest health payment plans, or financial background checks that may evade privacy laws and limit access to care.

Study Overview

Although much is known about the rising economic cost of cancer care compared to other diseases in the United States, there is little research to date on effective strategies to reduce patient financial burden. A first step is to better understand what type of challenges patients face and the events leading up to these challenges. This project uses a qualitative study design to explore the patient experience surrounding OOP costs, specifically for female breast cancer survivors on Medicare.

My study hypothesizes that there is little communication about costs early in treatment, and that increased communication could help alleviate individual burden. A literature review suggests that more timely communication could improve the patient experience, and in some cases, reduce financial hardship. More cost information, coupled with support services, may improve medical decision-making and in the long term, health outcomes. Although provider-patient communication is of specific interest, social workers and financial counselors contribute to this conversation. The study design also assumes that caregivers, friends, and family play an essential role in facilitating information about costs and devising strategies to cope with financial burden.

Research and Methods

In-depth, semi-structured telephone interviews were conducted until the criterion of thematic saturation was met. Interviews were conducted with a total of 22 participants selected from a prospective, nationwide survey completed by the Duke Cancer Care Research Program in 2011. I selected female breast cancer survivors, 65-75 years old and eligible for Medicare at the time of completion of the baseline survey for my study. Eligible participants must have received anti-cancer therapy for breast cancer (chemotherapy or hormonal treatment) within the past year. Participants were required to be English-speaking, literate, and with full capacity to be interviewed independently.

When the original survey respondents were sorted based on these criteria, there were 70 participants eligible for phone interviews. I interviewed patients who both a) did talk to their doctor about costs of care and b) patients who did not speak to their doctor about cost of care. Survey respondents reported significant/catastrophic, moderate, or minimal financial burden. Participants were not equally distributed in all categories, but efforts were made to speak to similar numbers of each type among the 70 eligible participants.

Data

Transcripts were analyzed using a thematic analysis approach, where major themes were coded, followed by minor themes. The major themes identified in this study represent different stages of communicating about costs. First, many survivors discussed the cost of their care only when the burden became unmanageable. Second, a number of participants discussed the process of identifying resources and determining eligibility. Third, several participants expressly stated that there is an associated need for self-advocacy in applying for assistance. Finally, several participants described significant emotional impacts of their financial concerns, including feelings of shame. They also showed immense gratitude for the assistance, and a desire to pay it forward to other survivors.

Interviews were also conducted with two **LIVESTRONG** patient navigators, a HealthWell Foundation Board Member, and the Oncology Services Revenue Manager for the Duke University Medical Center. These stakeholders reflected on the complexity of the current system in which cancer care is administered, with multiple providers and varying resources available.

Conclusions

In this detailed qualitative study, I gained insight into the varied situations in which older women with breast cancer experience OOP costs related to their cancer care. Through their narratives, participants described a fragmented continuum of care, without programs in place to safeguard financial health as well as physical health in a sustainable, reliable manner.

Many participants only considered discussing costs with their care team only once they were in financial distress – when it was too late. There were psychological and behavioral barriers to addressing this practical concern; many participants indicated that as long as insurance was paying, they were indifferent to the cost of their cancer care. However, once OOP costs became a significant factor, often as a result of the Medicare coverage gap, they were then willing to seek assistance. Additionally, when branded drugs became generic, participants became less concerned with the cost of their care. Many of the hormone therapies for breast cancer went off patent during the course of the study and significantly cheaper generic options became available for study participants. When this happened, they were not as interested in discussing the cost of their care.

These findings provide a nuanced understanding of the factors that impact the financial burden of cancer care for individual patients. My hypothesis was that early communication did not occur between patients and physicians about the cost of care – specifically, the individual burden related to OOP costs. These results suggest that communication may be happening, but that it is currently not helpful for patients. First, there is still too little communication overall, and it is mainly initiated by the patient. Only the most proactive patients appear to be seeking out this type of information. Second, communication is often too late. Patients will wait until they lose coverage or have other financial complications before trying to understand cost details relating to their treatment. Third, there are not sustainable solutions in terms of assistance – although help is available, it is highly variable and difficult to access. These conclusions suggest that national policy change could help with these systemic issues – validating the need for health care reform. However, given the deep partisan divides that exist, state and local solutions may be easier to implement.

Policy Question

In the context of health care reform, how can LIVESTRONG improve communication about the out-of-pocket costs of cancer care for its Navigation clients? Specifically, what resources could minimize the financial burden for female breast cancer patients receiving Medicare?

Introduction

LIVESTRONG’s mission is to inspire and empower anyone affected by cancer. To achieve this objective, the foundation follows a unique theory of change: care innovation, advocacy, and outreach all start with the experience of patients – who are considered cancer “survivors” from the day of diagnosis. Unlike other cancer foundations, LIVESTRONG does not fund scientific research to find cure. Instead, the focus is on the here-and-now problem of daily life with, and after, cancer. 81% of fundraising dollars support programs and services to improve the survivorship experience. The foundation strives to understand the physical, emotional, and practical concerns of post-treatment survivors. It is in this category of practical concerns – specifically, the out-of-pocket (OOP) financial burden associated with cancer care – that is the focus of this project.

Although much is known about the rising economic cost of cancer care compared to other diseases in the United States, there is little research to date on effective strategies to reduce patient financial burden. This project uses a qualitative study design to explore the patient experience surrounding OOP costs, specifically for female breast cancer survivors on Medicare. It builds on the results of a 2010-2011 national survey conducted by Dr. Yousuf Zafar of the Duke Cancer Care Research Program.¹ The 2010-2011 survey concluded that perceived and actual quality of care and patient satisfaction are negatively affected by financial burden. Survey participants employed coping strategies, including noncompliance with care and significant lifestyle alteration, to afford their treatment. I interviewed a subset of the original survey participants to get a more in-depth understanding of these challenges.

My study hypothesizes that there is little communication about costs early in treatment, and that increased communication could help alleviate individual burden. A literature review suggests that more timely communication could improve the patient experience, and in some cases, reduce financial hardship. More cost information, coupled with support services, could also improve medical decision-making and health outcomes. Although provider-patient communication is of specific interest, social workers and financial counselors are part of this conversation. The study design also assumes that caregivers, friends, and family play an essential role in facilitating information about costs and devising strategies to cope with financial burden.

LIVESTRONG will apply the recommendations derived from this research in two settings: 1) to inform future research, specifically the questions about practical concerns asked in

¹ Work in Progress, Zafar, Y. Duke Cancer Care Research Program, 2012.

the 2012 LIVESTRONG Survey for Post-Treatment Cancer Survivors to be launched in Spring/Summer 2012; 2) to guide service improvements to LIVESTRONG's Navigation Services program, which provides one-on-one professional support to anyone affected by cancer.

This report begins by setting the stage for cancer care and patient advocacy in the United States. Since the health care system is extremely complex, only information relevant to the issue of survivorship will be discussed. I will consider the cost of cancer care from an overall market perspective. I will then discuss cost considerations among providers, advocacy organizations, and patients. I will specifically consider considerations related to female Medicare beneficiaries, a population of interest because OOP expenses are particularly dramatic.

The second section presents the data collected and research methodology. I interviewed 22 female breast cancer patients aged 65-75 years old. These interviews capture a diverse range of viewpoints among the female Medicare population affected by breast cancer. As a baseline, this section also includes the findings from the 2010-2011 national survey, from whose participant group my interviewees were selected.

In the third section, I present an analysis of my findings, broken into four key aspects of the survivor experience: 1) discussing costs; 2) identifying resources; 3) applying for help; 4) the emotional impact of this process.

I conclude with a discussion of policy recommendations for LIVESTRONG to consider. I have prioritized these recommendations around three criteria: minimizing implementation costs, maximizing collaboration and buy-in among stakeholders, and maximizing applicability to clients of diverse backgrounds.

Background: Cancer Care and the Underinsured

Insurance and the Affordable Care Act

The 2010 Affordable Care Act extends insurance coverage to an estimated 32 million Americans over the next 10 years, primarily through expansions of Medicaid and private insurance coverage. It is assumed that expanded insurance coverage will improve access to health services, with the long-term goal of improving health outcomes and reducing overall costs on the system. For cancer care specifically, insurance has shown to create better outcomes through prevention. Uninsured patients are more likely to have advanced stages of disease at the time of diagnosis in comparison to insured patients, because they are less likely to seek preventive and diagnostic services.²

² Roetzheim, R. G., Pal, N., Tennant, C., Voti, L., Ayanian, J. Z., Schwabe, A., et al. (1999). Effects of Health Insurance and Race on Early Detection of Cancer. *Journal of the National Cancer Institute*, 91(16), 1409-1415.

Despite improved accessibility, the presence of insurance alone does not guarantee affordability. Many Americans are considered “underinsured” based on inadequate coverage for medical expenses. This population faces significant cost sharing or limits on benefits that create affordability obstacles. According to the National Coalition on Health Care, nearly two-thirds of personal bankruptcies filed in 2007 were related to medical expenses.³ Of those who filed for bankruptcy, nearly 80% were insured.⁴ Several studies have shown that underinsured patients will postpone care or avoid filling a prescription due to high costs.⁵

The problems related to underinsurance also extend to government payers, particularly for Medicare beneficiaries. The high cost of premiums, coinsurance, and prescription drug coverage causes Medicare beneficiaries to spend a substantial share of their household budgets on health care – on average three times compared to non-Medicare households.⁶ Seniors have more health needs than younger folks, but this trend is also due to benefit design. Unlike typical employer plans, Medicare does not have a stop-loss benefit limiting annual OOP spending.⁷ This creates a market for supplemental insurance, including Medigap and Medicare Advantage, with additional premiums for each plan. Over 91% of Medicare beneficiaries in 2009 had some form of supplemental coverage, each with its own set of premiums, cost-sharing plans, and co-pays.⁸

Despite this coverage, most seniors still spend substantial amounts out of pocket on health care expenses.⁹ In 2010, insurance premiums comprised more than two-thirds (68%) of average OOP health care spending among Medicare households. Medical services (such as hospital stays, physician services, lab tests) comprised the next largest spending component (16.0%), followed by prescription drugs (13.8%) and medical supplies (2.3%).¹⁰ Additionally, it is important to note that Medicare households with modest incomes (between 100-399% of the poverty level) have been found to be the hardest hit, spending a greater percentage of their income compared to the poorest and highest-income Medicare households.¹¹ Female beneficiaries are also particularly at risk – women on Medicare are disproportionately low-income, with fewer resources and more chronic conditions than men, and rely on Medicare significantly for retirement security.¹²

³ National Coalition On Healthcare, Available at: <http://nchc.org/issue-areas/insurance>.

⁴ *Ibid.*

⁵ The Kaiser Family Foundation, “Underinsured in America: Is Health Insurance Adequate?” 2002.

⁶ The Kaiser Family Foundation, “Health Care on a Budget: The Financial Burden of Health Spending by Medicare Households,” 2012.

⁷ The Kaiser Family Foundation, “Medicare: A Primer,” 2010.

⁸ The Kaiser Family Foundation, “Key Issues in Understanding the Economic and Health Security of Current and Future Generations of Seniors,” March 2012.

⁹ *Ibid.*

¹⁰ The Kaiser Family Foundation, “Health Care on a Budget: The Financial Burden of Health Spending by Medicare Households,” March 2012.

¹¹ *Ibid.*

¹² The Kaiser Family Foundation, “Medicare’s Role for Women,” June 2009.

The Medicare Part D prescription drug benefit that was introduced in 2006 is also administered by private plans with monthly premiums: either stand-alone prescription drug plans (PDPs) or Medicare Advantage prescription drug (MA-PD) plans. Prior to the Affordable Care Act, most Part D plans traditionally had a coverage gap, the infamous “doughnut hole,” where beneficiaries are required to pay 100% of prescription drug costs after total drug spending exceeds an initial coverage limit, until the beneficiary qualifies for catastrophic coverage. In 2007, an estimated 3.4 million Part D enrollees (14% of all enrollees) reached the doughnut hole.¹³

The Affordable Care Act specifically includes provisions to reduce Medicare OOP spending over time, including closing the Medicare Part D prescription drug coverage gap from 100% to 25% by 2020 (see Appendix, Exhibits 1-3) and eliminating cost-sharing for preventive services. However, these reforms are tempered by the policy challenge of financing Medicare and other large social policies for an aging population. If Social Security payments are constrained, for example, Medicare beneficiaries will have less monthly income available overall for health care spending.

Out-of-pocket costs, Cancer Care, and Navigation Services

Increasing OOP costs are particularly acute for cancer patients. Cancer is distinct in three ways: 1) it is widespread across the United States population, with 1 in 2 men and 1 in 3 women predicted to be diagnosed during their lifetimes;¹⁴ 2) it has a 64% survival rate¹⁵ which creates an increasing need for long-term management from both a medical and a financial standpoint; and 3) it is the third costliest diseases to treat¹⁶, with OOP costs rising more than total health care costs.¹⁷ This is a perfect storm from a patient perspective: in addition to physical and emotional challenges, patients face direct and indirect costs related to prolonged treatment (see Appendix, Exhibit 5). In a 2006 national survey of households affected by cancer, one-third of cancer patients reported difficulty paying their bills, and up to 25% reported exhausting their savings.¹⁸ In 2007, breast cancer patients with employer-based insurance had total OOP costs averaging \$6,250. This amount is higher than OOP spending for patients with asthma, diabetes, chronic obstructive pulmonary disease, or high blood pressure.¹⁹ Overall, Medicare households have higher

¹³ The Kaiser Family Foundation, “Explaining Health Care Reform: Key Changes to the Medicare Part D Drug Benefit Coverage Gap,” March 2010.

¹⁴ Horner et al, “SEER Cancer Statistics Review, 1975-2006,” National Cancer Institute, 2009.

¹⁵ Hewitt, Greenfield, and Stovall. “From cancer patient to cancer survivor: Lost in transition,” 2006.

¹⁶ US Department of Health and Human Services, Agency for Healthcare Research. Statistical Brief #331. Medical Expenditure Survey: “Top 10 Most Costly Conditions among Men and Women, 2008.”

¹⁷ Willey VJ, Pollack MF, Lawless GD. Oncology health care and patient out-of-pocket cost trends in a commercially insured population. *J Clin Oncol.* 2008;26 (May 20 suppl; abstr 6503).

¹⁸ The Kaiser Family Foundation. National Survey of Households Affected by Cancer, 2006.

¹⁹ Gabel, J., McDevitt, R., Lore, R., Pickreign, J., Whitmore, H., and Ding, T. Trends In Underinsurance And The Affordability Of Employer Coverage, 2004–2007. Health Affairs.

<http://content.healthaffairs.org/cgi/content/full/28/4/w595>.

average health care spending compared to non-Medicare households (\$4,527 vs. \$2,450, respectively, in 2010).²⁰

The proliferation of technological advances, medical specialization, new payment structures, and changing economic circumstances has made cancer treatment an extremely complicated experience. There are many agencies and organizations at the national, state, and local levels that provide financial assistance to cancer patients and their families. These include government agencies, pharmaceutical patient assistance programs, nonprofit copay relief organizations, and nonprofit organizations that help with practical needs. Each program has its own eligibility requirements and may cover only certain cancers or income levels. Cancer nonprofits are numerous, creating a fragmented ecosystem for patient assistance. There is frequent collaboration and referrals among different organizations, but the process has not evolved beyond lists and phone calls. One coalition, the Cancer Financial Assistance Coalition (CFAC) has created a database of organizations that provide financial assistance, searchable by cancer diagnosis, type of assistance, and zip code.

The challenge of resource coordination has led to the emerging field of patient navigation for cancer care. Navigation refers to individualized assistance and guidance to patients, their families, and caregivers to overcome barriers to care, improve patient outcomes, and facilitate timely access to resources from pre-diagnosis through all phases of the cancer experience.²¹ This definition builds on the work of C-Change, a national coalition of cancer organizations, and is used by the Oncology Nursing Society (ONS), The Association of Oncology Social Work (AOSW), and the National Association of Social Workers (NASW).

Over the past 20 years, navigation has expanded beyond clinical outcomes to streamline a variety of resources along the cancer care continuum. Navigators may have a variety of backgrounds, including nursing, social work, psychology, and community health. There are two professional organizations for nurse navigators: the Academy of Oncology Nurse Navigators (AONN) and the National Coalition of Oncology Nurse Navigators (NCONN). Navigators, along with community health workers, fit into the broader field of patient advocacy.

Preliminary studies have shown that these types of outreach programs create cost savings for providers, payers, and individual patients across different disease states.²² However, patient navigation is not currently recognized as a reimbursable service and requires funding outside of the typical fee-for-service provider model. Additionally, there are not widely adopted professional guidelines or accredited training programs for navigation. Each health care system has different interpretations for navigation programs, and training varies significantly without established standards in the field. This is likely to continue in

²⁰ The Kaiser Family Foundation, "Health Care on a Budget: The Financial Burden of Health Spending by Medicare Households," March 2012.

²¹ Pederson A, Hack T. "Pilots of Oncology Health Care: A Concept Analysis of the Patient Navigator Role." *Oncology Nursing Forum*, 2010;37:55-60.

²² Feder, D.O. "The effectiveness of a community health worker outreach program on health care utilization of west Baltimore City Medicaid patients with diabetes, with or without hypertension," *Ethn Dis*, 2003;13(1):22-27. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/12723008?dopt=AbstractPlus>

the foreseeable future, despite the field developing over time: beginning in 2012, the American College of Surgeons Commission on Cancer will add patient navigation as a new standard for program accreditation. Programs seeking cancer accreditation will be required to perform a needs assessment and provide “appropriate” navigation services to their clients.²³ This new standard uses local needs assessment and does not seek to prescribe a single program delivery model.

LIVESTRONG offers one such patient navigation program with free, comprehensive, one-on-one support to anyone affected by cancer. National services are provided via phone and email consultations. In-person services are available in Austin, Texas at the **LIVESTRONG** Cancer Navigation Center (LCNC), which opened in March 2011 and currently staffs two general navigators, two emotional support navigators, and one financial navigator. Clients contact the center and meet with a general navigator for an initial consultation, and may be referred to an emotional support navigator and/or a financial navigator. Referrals are also made to partner organizations nationwide for specific services (see Appendix, Exhibit 7).

Financial navigation is the individual service most often requested by clients of **LIVESTRONG**'s Navigation Services.²⁴ In 2010, over 23% of all **LIVESTRONG** Navigation services requested were financial in nature. To provide specialized assistance for this demand, **LIVESTRONG** has a contractual relationship with the Patient Advocate Foundation (PAF), another non-profit that specializes in employment rights and benefits, financial assistance, and debt management. **LIVESTRONG** pays PAF on a per-case basis for client referrals. The LCNC financial navigator for in-person consultations is staffed by PAF, but works out of **LIVESTRONG**'s headquarters.

Decision-making across the cancer care continuum

LIVESTRONG's concept of survivorship has far-reaching implications for health care delivery: instead of passive recipients of care, patients are assumed to be proactive. They are encouraged to demand quality, affordable services and seek greater transparency from their physicians. They manage their cancer care within the context of a rich life with practical as well as medical concerns. The survivor community provides peer support by sharing information and advocating for policy changes.

Despite a more informed cancer patient, information asymmetries between patients, providers, and payers complicate the medical decision-making process. Unlike many other countries, the United States, via the mandate of the US Food and Drug Administration, does not consider cost-effectiveness in drug-approval decisions. The task of assessing the value of different treatments often falls to individual patients and physicians. Despite this, discussions about comparative cost-effectiveness are not routine. A recent survey of US oncologists found that OOP costs are considered, but rarely discussed directly with

²³ Sein, Elaine. “Patient Navigation Becomes New Standard for Cancer Program Accreditation,” *Journal of Oncology Navigation & Survivorship*, Vol. 2, No. 2, April 2011. Academy of Oncology Nurse Navigators (AONN).

patients. Less than half of the oncologists who responded to this survey reported being comfortable with making cost-effectiveness decisions.²⁵

One additional consideration for decision-making is the point in time when patients consider discussing OOP costs. At its outset, poor behavioral incentives are created by insurance – specifically, moral hazard where the presence of insurance increases health care consumption. Particularly in cancer care, many treatments are framed as the difference between life and death. If physicians and patients are not footing the bill, they may be extra inclined to prescribe and consume more health care, respectively. Patients may only talk to their doctor about costs when they reach a gap in their insurance coverage. This study attempts to understand these types of nuances that may lead to financial burden.

Data and Methods

Study Design & Sample

I conducted semi-structured interviews with 22 participants selected from a prospective, nationwide survey of cancer patients that was completed in 2011. I selected female breast cancer survivors, 65-75 years old and eligible for Medicare at the time of completion of the baseline survey for my study. Eligible participants must have received anti-cancer therapy for breast cancer (chemotherapy or hormonal treatment) within the past year. Participants were required to be English-speaking, literate, and with full capacity to be interviewed independently. When the original survey respondents were sorted based on these criteria, there were 70 participants eligible for phone interviews (See Table 1 below).

I interviewed patients who both a) did talk to their doctor about costs of care and b) patients who did not speak to their doctor about cost of care. Survey respondents reported significant/catastrophic, moderate, or minimal financial burden. Although it was important to interview all three variants, I recognize that there are selection biases among those concerned about the financial burden of their care. All participants were already seeking financial assistance at the time of the survey. In the original study, participants who spoke to their doctor were found to be more likely to experience “significant” or “catastrophic” financial burden. Nevertheless, it was important to speak with each category of patients to understand the scope of their financial challenges, why or why not they spoke with their doctor, and the means by which they accessed financial assistance. Participants were not equally distributed in all categories, but efforts were made to speak to similar numbers of each type among 70 eligible participants (see Table 1 below).

²⁵ Berry, S. R., Bell, C. M., Ubel, P. A., Evans, W. K., Nadler, E., Strevel, E. L., et al. (2010). Continental Divide? The Attitudes of US and Canadian Oncologists on the Costs, Cost-Effectiveness, and Health Policies Associated With New Cancer Drugs. *Journal of Clinical Oncology*, 28(27), 4149-4153.

Table 1. Eligible participant distribution regarding cost discussion and financial burden (Female, Age 65-75, Breast Cancer)

	“Since your cancer diagnosis, did you have a discussion with your doctors about any difficulty in affording your cancer care?”	
“No” or “minimal” financial burden	<i>Discussion, low burden</i> 6	<i>No discussion, low burden</i> 3
“Moderate” financial burden	<i>Discussion, medium burden</i> 32	<i>No discussion, medium burden</i> 4
“Significant” or “catastrophic” financial burden	<i>Discussion, high burden</i> 21	<i>No discussion, high burden</i> 4

Additionally, I sought perspectives beyond the patient experience. I interviewed two cancer navigators in Austin, Texas: Sarah Gomez of LIVESTRONG and Brendan Bietry of the Patient Advocate Foundation. I also spoke to Dr. Donald Liss, a Board Member of the HealthWell Foundation and the Chief Medical Officer of Independence Blue Cross, a licensee of the Blue Cross and Blue Shield Association in Philadelphia, Pennsylvania. I also spoke to the Revenue Manager for Oncology Services at Duke University Medical Center.

2011 Duke Cancer Care Research Program Study

The 2011 study enrolled 307 participants who completed surveys between July 13, 2010 and July 1, 2011. Participants were recruited from two sources: the HealthWell Foundation and the Duke Cancer Institute. The HealthWell Foundation participants had contacted the foundation for financial assistance between June 2010 and May 2011. Participants enrolled at Duke were recruited during clinical visits for chemotherapy. Participants were mainly Caucasian (80%) women (88%), with a mean age (\pm SD) of 63.5 (\pm 11.0) years (see Appendix, Exhibits 8-9). 55% of participants were diagnosed with breast cancer. 56% were either married or partnered. 52% were retired and enrolled in Medicare.

76% of participants, many of whom lived on a fixed income, had a household annual income of less than \$40,000 (see Appendix, Exhibit 10). Almost all (99%) participants were insured and with prescription drug coverage (87%). Despite having insurance, participants spent a median \$428/month (median 15.8% of annual income) on OOP medical expenses. 66% were underinsured, spending greater than or equal to 10% of annual income on health expenses.

33% of participants reported a significant financial burden due to out of pocket expenses, and 9% reported a catastrophic financial burden. Participants most likely to experience high financial burden applied for financial assistance ($p=0.04$), had metastatic disease ($p=0.003$), and spoke with their doctor about costs ($p=0.049$). This finding is consistent with past research about patient-provider communication.²⁶ Self-reported coping strategies to save money included noncompliance with care (for example, avoiding filling

²⁶ Alexander, G. C., Casalino, L. P., & Meltzer, D. O. (2003). Patient-Physician Communication About Out-of-Pocket Costs. *JAMA: The Journal of the American Medical Association*, 290(7), 953-958.

prescriptions) or lifestyle changes (for example cutting back on basics such as food or clothing). 46% of participants used all or a portion of their savings, and 12% worked more hours to pay for their care.

In summary, the survey population was relatively homogenous, with the majority of respondents being white, female, and retired (65+ years old). Many were breast cancer survivors. This homogeneity provides an opportunity to follow-up with a group that may have had similar OOP costs related to their cancer care. Breast cancer patients specifically are routinely prescribed oral hormonal medications with monthly co-payments for at least five years. Additionally, past studies have indicated that elderly patients on Medicare may have more difficulty with treatment compliance as a result of these OOP costs.²⁷ Several of these medications came off patent in 2010-2011, during the period of the original study, directly affecting participant OOP costs (See Appendix, Exhibit 11).

These experiences are applicable for LIVESTRONG's national client base. While this qualitative study may not represent the experiences of all cancer survivors due to its voluntary nature and small sample size, its findings can provide important insight into practical concerns related to the survivorship experience.

Data Collection

In-depth, semi-structured telephone interviews were conducted until the criterion of thematic saturation was met. Interviews were conducted with a total of 22 participants. Participants were called in alphabetical order from a pool of 70 eligible candidates. Although the selection process was not completely random, no preference was given to one candidate over another in selection, apart from monitoring to ensure that a geographic spread was achieved. Demographic and other characteristics of the participants are detailed in Table 2 below.

The interview protocol included both closed and open-ended questions relating to a number of issues, including discussing costs with a doctor, accessing cancer professionals besides a doctor, identifying financial assistance resources, applying for assistance, and coping strategies (See Appendix, Exhibit 12). Participants were asked to recall a discussion they had with their doctor about costs, if any. Specific types of costs (ie., premiums, co-pays for doctor visits, co-pays for pharmaceuticals) were intentionally not specified in the research instrument to get the largest possible range of responses. Participants were asked whether they initiated this discussion with their doctor or vice-versa, and how they might approach this topic differently with the hindsight of their experience. The interviews were recorded and subsequently transcribed.

²⁷ Streeter, S. et. al, 2011. Patient and Plan Characteristics Affecting Abandonment of Oral Oncolytic Prescriptions. *Journal of Oncology Practice*, 7(3S), 46s-51s, and Neugut et. al., 2011. Association Between Prescription Co-Payment Amount and Compliance With Adjuvant Hormonal Therapy in Women With Early-Stage Breast Cancer. *Journal of Clinical Oncology*, 29(18), 2534-2542.

Table 2. Participant Characteristics

Characteristics	N=22 (%)
Gender	
Women	22 (100%)
Race-Ethnicity	
White/Caucasian	21 (95%)
Black/African-American	1 (5%)
Marital Status	
Married	13 (59%)
Divorced	4 (18%)
Widowed	4 (18%)
Living with Partner	1 (5%)
Geography	
Northeast	3 (14%)
Southeast	7 (32%)
Midwest	6 (27%)
Southwest	2 (9%)
West	4 (18%)

Table 3. Actual Participant Distribution regarding cost discussion and financial burden (Female, Age 65-75, Breast Cancer), selected at random

	“Since your cancer diagnosis, did you have a discussion with your doctors about any difficulty in affording your cancer care?”	
“No” or “minimal” financial burden	<i>Discussion, low burden</i> 2	<i>No discussion, low burden</i> 2
“Moderate” financial burden	<i>Discussion, medium burden</i> 6	<i>No discussion, medium burden</i> 2
“Significant” or “catastrophic” financial burden	<i>Discussion, high burden</i> 7	<i>No discussion, high burden</i> 3

Data Analysis

Transcripts were analyzed using a thematic analysis approach, where major themes were coded, followed by minor themes. The major themes identified in this study represent different stages of communicating about costs. First, many survivors discussed the cost of their care only when the burden became unmanageable. Second, a number of participants discussed the process of identifying resources and determining eligibility. Third, several participants expressly stated that there is an associated need for self-advocacy in applying for assistance. Finally, several participants described significant emotional impacts of their financial concerns, including feelings of shame. They also showed immense gratitude for the assistance, and a desire to pay it forward to other survivors.

Interviews were also conducted with two LIVESTRONG patient navigators, a HealthWell Foundation Board Member, and the oncology services revenue manager for the Duke University Medical Center. These interviews are summarized below. These stakeholders reflected on the complexity of the current system in which cancer care is administered, with multiple providers and varying resources available.

Results and Discussion

Themes

1. Discussing Costs

One theme that emerged from the interviews was that the level of OOP burden influenced *if* and *when* costs were discussed. Insurance coverage is known to create moral hazard, where utilization rates increase if beneficiaries do not personally bear the cost of their care. A number of participants indicated this was their experience.

“Well, there was no need to [discuss costs at first] – I had the insurance.” (74, Texas)

“I didn’t ask him about the cost of my care, because I had the insurance. I wouldn’t have felt that comfortable if it did come up, because I don’t have any money. And I know it would be expensive because it’s expensive to go there for practically anything.” (72, Virginia)

“I didn’t because I knew I was going to take it and my insurance company was going to pay for it. So I didn’t really discuss the financial parts of it...**[But]** actually I did initiate with HealthWell to find extra money when we didn’t have money after the first year of paying for the Femara, which was very expensive. Yes, I did discuss it with him then and he filled out the paperwork for me.” (68, Pennsylvania)

Many participants brought up costs only once they reached the Medicare coverage gap. At this point their fixed budget was suddenly constrained and they were responsible for 100% of their medical costs, including their cancer care. Several of these participants reached the Medicare gap within 4-6 months of the calendar year.

“I was covered with my Medicare and I had BlueShield. So the cost was not a big issue with me. And then when he put me on the ongoing cancer drugs, which I am still taking, there was a problem because of the co-pay. You know, once you go into the donut hole. Both of the drugs that were being used to treat breast cancer were still branded pharmaceuticals. One was Arimidex and the other one was Femara, and I complained because the copay was \$300 and \$400. That was a real issue for me.” (71, California)

“It put me into the donut hole, which is another reason that I talked to her because I am also on cholesterol medication, blood pressure medication, and a sleeping pill and an antidepressant.” (68, Oregon)

“Each year I would go in the Medicare gap somewhere in the first of June. It [Medicare] wouldn’t pay for my other medications, nor my cancer medications. You have to pay 100% until you spend up to \$4500. I never did spend up to \$4500 to put me into the catastrophic category.” (67, Texas)

"The new medication was \$500 a month. So that immediately puts you into the \$2000 range in 4 or 5 months. So that means everything else is now not covered. So, I went back to the doctor and I said I'll go back on Tamoxifen, I'll go back on anything that's cheaper because I am not going to spend that kind of money." (68, *Massachusetts*)

Participants mentioned that the introduction of a generic drug to the market diminished their concern about costs.

"Every doctor I have, which are many, I mention that the copays are getting more expensive to see the doctor, and the copays on the drugs. I have a drug that has gone to generic, for a \$3 copay. That helps." (69, *Michigan*)

"[My doctor] ...is the one who said go to the Novartis website to see if I could get some funding for Femara, which is what I did. And so they repaid me the co-pay for about a year and then by that time it had gone to generic so I didn't have to re-apply." (71, *California*)

"I was going to have to go on Femara, and even with the Medicare drug plan, it was about \$140 a month, and my total income is about \$1700 a month, and that's a lot of money to spend. So I was looking for ways to help pay for that – because my income was usually low enough to qualify for drug assistance if they didn't look into my assets. Most of what I do have, I put into annuities, that's why I have the income I have. Meanwhile Arimidex, which is similar to Femara, became generic, and that's what I'm on." (65, *Florida*)

Several participants who initiated a cost discussion with their cancer team were pleased with the resulting actions. Professionals were responsive to providing economical treatment alternatives or resource referrals.

"I never gave it any thought. Went home, filled the prescription, never looked at it. Then, when I got my bill, I almost had heart failure. They didn't mention it. When I went back I ended up speaking to his nurse practitioner, not so much the doctor. And I said to her, 'I'm not taking this if it's going to be \$500 a month.' And she says, 'Oh my god, that's unreal. No, no, no we can put you on something just as effective.'" (68, *Massachusetts*)

"I just really didn't want to switch but I realized it was just unbelievably expensive and so then I talked to him and asked if he would be comfortable with me taking something else. And he said he would be very comfortable with me taking Arimidex and there was a generic for that and he thought it would be fine so he had no problem switching me over to that." (70, *West Virginia*)

"I spoke with her, and told her that uh...my husband died, and we were in debt, I was sick, he was sick, I lost my house, all this stuff, and I told her, that I could not afford to take the Femara, and she said well, you can apply for help, I'm sure you can get help...ok, so then I did, I started applying for help with the copay, and I got help, and each year you have to go through the very same thing." (71, *South Carolina*)

Many participants whose doctors initiated a conversation about the costs of care had a positive experience. Several of these doctors brought up costs particularly when the participant transitioned from one form of therapy to another (ie, chemotherapy to hormone therapy).

"The doctor didn't bring it up at first. He brought it up when I got off the chemo." (72, *North Carolina*)

“My doctor brought it up...She said that if we needed to do chemo, you would have to be here every so many days. If radiation, you would need to be at the radiation area every day for so many days and this is what it might cost...fortunately I could get by without having the chemo, but she did discuss it. And she did discuss the radiation that I might have to go with, but I didn't have to get it. (67, Texas)

Participants had mixed views on whether the physician should discuss costs at all. Some participants said they would feel very comfortable if their physician had mentioned costs. Other participants believed that dealing with financial concerns was not the physician's primary role.

“Yes, oh yes. With my oncologist I would feel very comfortable.” (68, Pennsylvania)

“I just felt that it was a matter I didn't want to get into with my oncologist because he is there to treat my cancer not to work out my financial problems...I don't know if I would have asked the doctor, I kind of feel like that is not their role.” (70, Ohio)

“With my diagnosis was my doctor. But the grants or whatever I need... there's a financial person.” (70, Florida)

A number of participants spoke about the challenge of decision-making when it comes to cancer treatment. When decisions felt like life-or-death, they did not feel that they had a choice in absorbing the costs of their care.

“I wanted to stay alive...it wasn't a choice.” (66, Connecticut)

“Costs didn't factor in – I was just thinking about the medical procedure. This is what she [my doctor] said I needed, and that's what I got.” (66, California)

“When I first was diagnosed, I just accepted that this is part of getting better to take this medication. I was so glad I didn't have to have chemotherapy and could just take the medication and see how it worked over time. I was really happy to do that and just accept that okay I've got to absorb the cost.” (68, Oregon)

“I just took my medication, I didn't ask, I gotta go because they tell me too, and it's supposed to be helpful to me, for my health. So I didn't. But like I said, after a while, I did ask questions. Always ask questions. You have to.” (66, Connecticut)

2. Finding Resources

Many participants mentioned that their doctors provided drug samples as a temporary fix. This may have hindered conversations about more sustainable solutions regarding financial concerns.

“I didn't talk [to the doctor] because he's been giving me the medicine, the Femara.” (68, Kansas)

“I got the \$20 help on the co-pay type thing from the pharmaceutical company. But then, when I reached what they call the gap, or the donut hole, he had to give me a couple of samples, because I couldn't pay the full price. I could pay the co-pay but not the full price.” (71, South Carolina)

"We had several conversations and at one point a couple of times my doctor gave me a months' worth of drugs. And then I had four months left to go and the price went up again, and she switched me to another drug for those last few months that was cheaper. The first year was pretty affordable, and the beginning of the second year is when it took a big leap, and I called them [my doctors], they wrote a letter for me saying that I needed to have this drug, since Medicare was saying use something else." (66, California)

"[The doctor said]...'I can give you free medication when I have it on the shelf'...and I said 'I can't live like that, coming in here to get free medication, but you not having it, when I need it?'" (67, Texas)

Several participants described the experience of going to a financial counselor as disjointed from the oncologist visit and other support services.

"The financial counselor just said what it was going to cost and I was told what I was going to pay. I wish I had known though that there were options for me. Like I had to go buy a wig and nobody offered that and I see now that it is offered there where I go. They have scarves, everything, and nobody told me that was available to me." (66, Arizona)

"You would see [the oncologist] and you would feel good that treatment was going to be doable, and then you'd walk out and they'd say that the financial advisor lady wants to see you, and she'd sit you down and say, 'So how are you paying for this?'" (65, Florida)

"Well the doctor never talked about money, she didn't say it would be free, but that she'd never turn down a patient. And then the financial person, she was the one who collected the money, it was hard to get out of there without seeing her. And at the hospital, they had a lady there telling people to take out a second mortgage to pay for chemo treatment." (65, Florida)

A few participants explained that they trusted medical professionals and/or Medicare to provide accurate information about their coverage and eligibility for financial assistance.

"I said I don't think I qualify. And she said you don't know. Send me your financial statement and your income tax report from the year prior. I did and I met the social worker there at the clinic and I qualified for some from HealthWell and I so I got a grant of \$2,000 from HealthWell for a year." (68, Oregon)

"I don't have a computer so I don't do any research online. I just have to trust the Medicare and the WellCare. What can I do? You know I'm not able to research anything so I just have to trust that I'm getting what I'm supposed to. And I don't quite understand, I mean I'm glad for the ObamaCare, but a layperson doesn't understand how there was a donut hole and that it's supposed to be closed now." (70, Florida)

One participant referenced CURE magazine as a resource that helped her get ideas on what questions to ask her doctor. Another participant mentioned that she called the Dana Farber Cancer Institute for resource referrals. Another participant mentioned Wings as a helpful resource.

"I have a subscription to the CURE magazine and I read it carefully and try not to throw them away. It addresses not just cancer and working with cancer problems but also the rest of your life so financial, economic issues are discussed and it probably would have led me to ask about [the cost of my care]." (68, Oregon)

"I called The Dana Farber Cancer Institute. It was some person that could give you advice. When I got into the donut hole and had to finish out the year, she put me in touch with the HealthWell Foundation and I could finish the year with the Femara and HealthWell picked up the money. And then she gave me the name of Rx Outreach." (68, Massachusetts)

"Wings is a wonderful program. They helped when I had to have chemotherapy, for my daughter to come over to help me with the medicines – every two weeks they paid her gas. That helped because she lived a couple hundred miles away. So, there are programs out there. It's just that you have to try and find out this stuff." (67, Montana)

3. Applying for Help

Participants described a complex application process, where physicians are often the gatekeepers of information required for eligibility. Participants must reapply each year to remain eligible.

"I got the paperwork, I filled it out myself, went in and said all I need is your numbers and your signature, to be able to apply for free medication...The doctor finally signs because I've badgered him to death...but...you have to reapply every year. (67, Texas)

"I've had no one to help me, to ask questions to help me, I've been on the phone sometimes, for two hours, trying to get through to Social Security, and all these programs and never can, I mean, you finally, they wear you down, they just absolutely wear you down, you listen to so many recordings, but I don't have anybody. I only have me." (71, South Carolina)

Several participants mentioned that the reimbursement process, once they were approved for assistance, was equally complicated.

"It took an act from Congress to get the check back from them. I don't know if they didn't think I paid for it... I can't tell you how many times I had to send copies of stuff from the bank and whatever. It was quite an ordeal that I didn't want to have go through again if I didn't have to." (67, Montana)

A few participants reflected on the challenges of cancer care on a fixed budget, and the eligibility levels for financial assistance.

"I will tell you this, it costs us \$712 out of pocket every month to keep the insurance and to pay for medication. Sometimes more, sometimes less. By the time you pay for the insurance, and prescriptions, \$45 per prescription, it is a lot when you're on the salary that we're on. Plus my husband has to have medication and treatment. We're down to \$50 a month when our checks come in. We're very grateful is that we don't have to pay for a house and a car. If we had house and car payments we would have sunk...I'm 160% above poverty level, why can't I afford health care? (67, Texas)

"After a while, because I had to pay for my co-pay, my insurance, my bills, I did ask questions – can't you do something else, can't you do something here, at the hospital? And the social worker said you can inquire, this and that, but you gotta make \$10,000 a year to get help. C'mon, who lives on \$10,000 a year, husband and wife? I didn't apply cause I made more – I used to make more. Like I said, I called the HealthWell Foundation, they were very helpful, but like I said, after 6 months, they said sorry, the funds are gone." (66, Connecticut)

Most participants cited self-advocacy as a key trait that has helped them cope with the financial impact of their care. They acknowledged that this is challenging for a patient currently undergoing strong cancer treatment – especially chemotherapy.

“I don’t know if I would have asked the doctor, I still kind of feel like that is not their role, but I feel like I would have made more strides to letting people know the financial difficulty that I was in. I think I would have sought out something more from the hospital itself, other than they did, like I said, excuse some of my bills after I’d got on them several times and told them the situation. But again it was all on my part, if I had not done it, it wouldn’t have been brought up, I am absolutely certain.” (70, Ohio)

“I try to when my mind is really coherent, because there are times when it still isn’t, to check everything. Every year I check with Medicare, and those people if you tell them what drugs you’re taken, they will tell you the best plan to be on, and I keep changing your drug plan.” (65, Florida)

“I know there’s people out there that will go to a clinic, and they’re going to be diagnosed, and they are just going to accept the word “No.” Because they’ve not worked in the medical field, and they don’t know that you can go and face a doctor, and tell him that he doesn’t know where you are right now, he knows your health, but he doesn’t know how much money you don’t have, to pay him. And you’ve got to have someone to speak for you. A doctor is not God, he’s a human being, just like us. Some of them think they are, but they’re not. So you’ve got to have someone to speak for you. I didn’t, but I was able to do it myself. Now if I had been taking chemo and radiation I might not have been able to.” (67, Texas)

4. Emotional Impact

A few participants reflected on the feelings of shame and depression related to asking for financial assistance.

“I sent them everything – probably as thorough an application as applying for a mortgage, including tax statements, and after a month or two they wrote back and said yes, you’re eligible, so the next time, pay the bill, and we’ll reimburse you. So I did that, and I never heard another word from them... they’re remote, and they make you call, and humble yourself, and beg...and then they ignore you.” (66, California)

“I talked to a social worker just about my depression and a lot of it was surrounding finances...it was terrible for me to be in that position because I always prided myself on paying all my bills.” (70, Ohio)

Many participants also expressed gratitude and a desire to pay back the assistance organizations. Several participants spoke about wanting to help other survivors and making sure funds were available to individuals that were most in need of assistance.

“There is help out there, I know I felt very grateful for what I got. And I try to donate to everything I can for cancer because I know other people in the same boat.” (67, Montana)

“When my doctor gave me a 12 month supply, I felt it was only fair for me to call the HealthWell Foundation and let them know what happened and that I wouldn’t be sending in any more receipts until I finished taking what the doctor was giving me. I felt like someone else should have it, you know what I’m saying? I feel like I could take advantage but I shouldn’t.” (73, Georgia)

"I don't want to sound like I'm complaining, because there are people living in vehicles, and homeless people, and hungry people, and I pray for those all the time, and I'm very grateful that I have a shelter over my head, and food to eat, and take my medicines – although I struggle." (71, South Carolina)

"I never did apply for the gas but I should have done because the gas started going up so much compared to the initial months of treatment. I just paid that out myself because I was so grateful to get the grant that I didn't want to over do it, you know. So I have been bearing the brunt of that myself...CancerCare...have been wonderful to me. I wish I had money to pay them back, maybe if I win the lotto someday. It's \$200 million this week." (70, Florida)

"We don't travel, we don't do anything now because it's a \$100,000 illness... you can cry the woes but I'm just grateful that I'm still alive and everything is fine and I was able to pay everybody. That meant a lot. Because I didn't want to have to sell my home and that's probably what we would have to do to pay our medical bills. What are you going to do? Caught between a rock and a hard spot." (67, Montana)

Other conversations: Interview with LIVESTRONG Patient Navigators

I spoke with two navigators: a navigator dedicated to general resource management, and a navigator that specializes in financial assistance. Each offered insight into the patient experience, and corroborated many of the insights from the survivor interviews. Their perspectives are summarized below.

1. Working with the Medicare Population

Specific to working with the Medicare population, the navigators explained that additional "hand-holding" was required. Older survivors have varying degrees of cognition and tend to get exhausted by the process. A navigator needs to repeat herself often, and help focus the patient on the issue at hand. Co-morbidities complicate patients' lives from a financial standpoint, in addition to creating more complicated physical and emotional situations. The navigators agreed that it is helpful to have a caregiver or relative also on the phone or in a consultation to help facilitate information and ask questions.

The navigators also mentioned that this population has complex opinions regarding paying for their treatment. On the one hand, there is a sense of resignation, which can create conflicting behaviors. Some older patients may be willing to take on more financial risk, whereas others may not be willing to do so, given that they are older and out of the workforce. Some patients may have inflated expectations for their insurance, creating disappointment and frustration when coverage gaps arise. Finally, the navigators described a strong sense of pride among this population. The process of asking for help, when they have never in their lives done so, may be particularly challenging. This perspective likely varies by demographic. For a less affluent population with more experience with assistance programs, such as low income women of color, there may be different sentiments surrounding asking for help.

From the navigators' perspective, patients are happy to have more information. It might not change their outcomes, but being able to have someone to talk to, to take the time to

explain things, helps. One client described it as “just what she needed” – talking to a live person versus calling automated phone lines of federal and state agencies. Although LIVESTRONG was not able to help her, she had still experienced a complete change from being agitated and overwhelmed to feeling calm and proactive.

2. *Systemic problems in cancer care*

The navigators described several systemic problems that likely extend beyond the Medicare population. Patients want to seek out the best doctor possible for their cancer care. Navigators must remind patients of all the indirect costs of their treatment, including transportation and parking – that create OOP costs even if they have excellent health insurance. Different resources such as fertility preservation can actually create costs before the cancer treatment itself starts. Additionally, smaller clinics may put patients at a disadvantage. Compared to a comprehensive cancer center, these offices often do not have a financial counselor or dedicated social worker who proactively provides navigation services to patients.

The importance of timing was also emphasized by each navigator. There is a critical window to apply for many resources, and patients should seek assistance at the beginning of treatment. The financial navigator mentioned that more people seek assistance when it is too late (ie, in a significant or catastrophic financial situation), as opposed to patients coming early in their treatment. He acknowledged that there is high uncertainty in this process in that it is difficult to forecast costs, and eligibility must be reassessed each year. Many grants are funded by pharmaceutical companies, and patient assistance organizations need to comply by their rules – and are also subject to sudden budget cuts.

The general navigator questioned whether patients would be comfortable discussing their financial position with their physician. They are already exposing themselves physically, she said, and they may not want their physician know about their finances. She suggested that a clinical social worker would be better suited to this role. The physician should be aware and offer options and help with eligibility paperwork, she said, but someone else should be providing the consultation with the patient about financial concerns.

She also was hesitant to suggest that physicians would be able at all to provide direct financial guidance to patients. This role requires the professional to be continually aware of available grant funding as well as each individual patient’s financial situation. Time constraints may make this impossible for physicians to provide timely and relevant information to patients. For example, in three years, a grant went from \$1500 to \$150. This happens to the Patient Advocate Foundation “all the time” when donors withdraws funding. “How could a physician be expected to know this?” she asked.

Moreover, the current solutions (ie, grants) seem unsustainable given the scale of cancer incidence, and rising costs of care, among an aging population in the United States. The navigators voiced the opinion that there may be not enough funding to go around for all Medicare-eligible patients, especially with something so pervasive as breast cancer. Scarce resources create a competitive landscape for many individual cancer organizations trying

to secure donor funding. Both navigators reflected these organizations do not share information as well as they should.

3. Recommendations from the navigator perspective

The navigators had several recommendations based on their experiences serving patients with financial concerns:

- ***Continue to expand the field of patient navigation.*** This can take the burden off both patients and physician. It is important that this happens at diagnosis – could there be a mandate to meet with a financial counselor for all patients? Insurance coverage for this type of service is key. The goal would be to prevent unpaid bills from collecting dust while funding is still available and the patient is still eligible. Navigators should be trained in the specifics about insurance and be compassionate. Social workers can staff this role if specialized navigators are not available.
- ***Train professionals for the task of communicating financial information to patients.*** From the point of view of a navigator, physicians need to be willing to help patients get assistance, but may not be the right person to facilitate a conversation about grant eligibility or personal financial responsibility. The best doctors probably do find the time to connect with their patients around these issues. Doctors do need to be available to justify medical treatment/medical needs for the insurer.
- ***Use technology and collaboration to improve resource identification process.*** Navigators are still using lists to identify resources. It would be great if organizations could put resources on one list only, continually manage this list, and provided eligibility criteria for each type of assistance. There is a need for more clarity in this area, especially for small foundations. Navigators spend precious time searching on the web and making calls, and vice versa – sometimes small foundations call directly with new funding opportunities, but often this can only fund a few patients.
- ***Simplify the application process for grantees.*** In the past year and a half, PAF has created internet portals to try to simplify the process, with electronic signatures, PDFs, etc. The process could continue to be simplified, either online or over phone. Ideally, the navigator or social worker does this for the patient.
- ***Develop or adapt technology solutions to facilitate efficient patient navigation.*** Software could be used to predict red flags about their patients' ability to afford care. This could benefit the hospital to facilitate payment, eliminate bureaucracy, and highlight relevant resources. This type of software does exist. However, it raises questions about patient privacy and data use in a provider setting, and may restrict access to care.²⁸

²⁸ Berner, Robert and Chad Terhune. "Hospitals X-Ray Patient Credit Scores," BusinessWeek, November 20, 2008.

Other conversations: Interview with Dr. Donald Liss, Senior Medical Director, Independence Blue Cross and Board Member, HealthWell Foundation

Dr. Donald Liss cited two specific challenges in patient-physician communication: 1) **ignorance of cost information among both parties** and 2) **discomfort and awkwardness in having this type of conversation.**

First, in Liss's experience, at the point of discussing treatment options, the odds that the physician or the patient know the entire cost of therapy, or at least the costs to which the patient might be exposed (ie, not covered by insurance) are "like zero." He said this might not make a difference if it is a generic prescription for a blood pressure medication, but may matter a great deal for a very expensive chemical agent or specialty drug. Further, the ability to get this information, without "going into heroics," is a significant challenge. There are practical realities of who will supply the therapy, when is the deductible going to be attached, what is the co-insurance, and the OOP limit under the terms of a patient's insurance policy. All of these things bear on the final cost figure. As a result, physicians may make assumptions that are inaccurate, or just "discount and avoid it."

Second, Liss described a discomfort or awkwardness in initiating this type of conversation. Physicians are extremely uncomfortable talking about financial consequences of therapy, or financial matters at all, with their patients, he said. In his opinion, educated assumptions about willingness to pay and available resources for the patient, should not be underestimated. And yet, he observed, this type of focus is "not a big feature in the medical school curriculum." Similarly, patients in his opinion are perceived as uncomfortable, embarrassed, or worried that their treatment may differ based on how they respond to questions about finances. He thinks this effect may be compounded when it is a caregiver as opposed to the patients themselves.

Additionally, Liss spoke about the complexity of cancer care, which adds to OOP costs. Often it is not just one drug or one chemotherapy regimen, but rather multi-modality therapies, including surgical procedures, hospital admissions, radiology treatments, specialists, primary care physicians, etc. He mentioned that oncology practices are now bigger entities than they were 10-15 years ago, and often have a financial counselor on staff to explain the implications of each therapy and secure coverage and/or supplemental funding. His impression is that these referrals to these counselors are often made after a chemotherapy regimen is recommended. If it is determined that a patient cannot practically afford the treatment, the physician is asked to consider a Plan B. However, this is more of an exception than an iterative process. LIVESTRONG's Navigation Services could be particularly helpful for smaller clinics, where there are not financial counselors on staff.

Concerning price transparency, Liss spoke about demand pressures in the private health insurance market to make prices more available to health consumers. Several national health plans have created online pricing tools to allow consumers to determine their OOP costs. As consumer-directed health plans (high deductible plans) become increasingly popular, consumers will continue to demand differential cost information from their

insurance payers. Hospitals and providers, however, have less incentive to provide cost information beyond the list price. Medicare, at least, has consistent cost-sharing requirements across all providers.

Liss commented that patient assistance organizations are a “band-aid, not a cure” to a very complex problem. The HealthWell Foundation does what it can to assist patients with the funds it has, but it is not long-term solution. At the health care systems level, there are some “unpalatable options” for many constituencies, such as price controls for certain services or restrictions on benefit design, so there are not the kinds of OOP exposures that we currently observe. Additionally, he mentioned that it is sometimes equivalent to a full-time job to hunt for an assistance program – which a patient may or may not be eligible for.

Finally, Liss observed that HIPAA restrictions create additional complexity in applying for assistance. There may be ways to help people execute the permissions that allow confidential information to be shared, to make it easier for patients. Similar to a power of attorney, navigators could collect medical records from the doctor, speak with the insurance carrier, and interface with assistance organizations.

Other conversations: Interview with Revenue Manager, Oncology Services, Duke University Medical Center

The Revenue Manager acts as the liaison between patients and the billing department. This individual had the perspective of working at US Oncology, a private practice, for 6 years, and at Duke University Medical Center (DUMC) for 9 years, a major academic medical center. In her experience, private practice operations were more cohesive and streamlined. At DUMC, she has experienced long wait times and difficulty maintaining schedules.

In terms of costs, she experienced more cost transparency in private practice. Physicians take on more financial risk – drugs may or may not be covered. As a result, they are more transparent in making sure their patients will be able to cover the costs of their care, one way or another. At an academic medical center, seeing patients in clinic is just one aspect of a physician’s job. A mix of academics, teaching, and lab/research creates a diversified focus that may obscure the need for cost transparency.

Billing is a complicated process that gets split between physician groups, technology, and the hospital. Drugs and devices may be separate or bundled. In the hospital setting, they are more likely to be bundled. For Medicare patients, payment varies by geography, teaching, etc. but also by setting for each individual procedure (See .4 below). The Revenue Manager said Medicare was one of the largest payers for Duke’s cancer clinics. Most physicians, in her experience, do not know the amount billed for each type of procedure they perform.

The Revenue Manager occasionally has direct contact with people with billing issues. Typically, there are customer service patient representatives who assist patients with charity care and payment plans. The billing office can also assist with letters of medical necessity for OOP assistance eligibility.

Table 4. Medicare Payment Varies by Setting (Source: David Ridley, PhD, Health Sector Management Program, The Fuqua School of Business at Duke University)

Physician Office	Hospital Outpatient		Hospital Inpatient	
Physician services	Supplies, devices, and overhead	Physician services	Supplies, devices, and overhead	Physician services
Paid using Medicare physician fee schedule	Paid using outpatient prospective payment	Paid using Medicare physician fee schedule	Paid using inpatient prospective payment	Paid using Medicare physician fee schedule

Discussion

In this detailed qualitative study, I gained insight into the varied situations in which older women with breast cancer experience OOP costs. Through their narratives, participants described a fragmented continuum of care, without programs in place to safeguard financial health as well as physical health in a sustainable, reliable manner.

Many participants described that they only considered discussing costs with their care team only once they were in financial distress. There were psychological and behavioral barriers to addressing this practical concern; many participants indicated that as long as insurance was paying, they were indifferent to the cost of their cancer care. However, once OOP costs became a significant factor, often as a result of the Medicare coverage gap, they were then willing to seek assistance. Additionally, when branded drugs became generic, with minimal OOP costs, participants became less concerned with the cost of their care. Many of the hormone therapies for breast cancer went off patent during the course of the study and significantly cheaper generic options became available for study participants (See Appendix, Exhibit 11).

Three of the interview participants reported in the initial survey that they had a significant or catastrophic financial burden, but that they did not speak to their doctor about difficulty affording care. However, by the time of the interview all three of these participants had spoken to a professional about the cost of their care. Two of the three participants noted that their treatment changed, making their financial situation more dire, and as a result they subsequently spoke to their doctor. In both of these situations, the doctor initiated this conversation, and provided samples and contact information for HealthWell. The third participant spoke to a social worker and a financial counselor about her costs. She believed that her oncologist was not the right person to speak to about financial concerns. These insights provide insights into the timing and real or perceived barriers of these conversations. It is recommended to focus on this group in future research.

This study has a number of strengths. The advantages of its qualitative approach provide access to detailed narratives of Medicare patients, a population critical to the future of oncology care given overall aging trends and cancer incidence in the US population. These narratives yield data that may not be readily available through quantitative research with specific hypotheses. Additionally, the study design of a follow-up with participants of a national survey allows for a mixed methods approach in future analyses.

Participants had similar demographic and socio-economic backgrounds, which assist in strengthening the generalizability of themes. Purposive sampling was used to create a geographic spread, but otherwise participants had similar OOP costs due to their breast cancer diagnosis, stage of cancer treatment (mostly hormonal therapies, after radiation, surgery, and/or chemotherapy), and Medicare coverage. Overall, these factors assisted in obtaining a diverse set of perspectives from participants with similar circumstances.

There are also certain limitations of this study. In the open-ended interview protocol, no single type of costs (premiums, coinsurance, prescription drugs, indirect costs, etc.) was specified. As a result, participants may have had different perceptions about what comprised “the cost of care” or “financial burden.” This strategy allowed for an unprompted, diverse range of perspectives, but may have limited the depth of information participants chose to share, particularly with an older group of participants. It is recommended that future studies test whether this is a valid concern.

Recommendations

LIVESTRONG's Opportunity

LIVESTRONG, dubbed the “world’s most innovative cancer foundation” in a 2010 FASTCOMPANY magazine cover story, has immense credibility in the field of cancer survivorship and is regarded as a leader in developing programs that empower and assist people affected by cancer.²⁹ As an effective patient advocate, it is on the cutting edge of clinical research and maintains strong relationships with providers through the American Society of Clinical Oncology (ASCO) and LIVESTRONG Centers of Excellence. It also frequently partners with other cancer advocacy organizations and has worked directly with influential policymakers, including New York City Mayor Michael Bloomberg and the Clinton Global Initiative, on public policy initiatives. For all these reasons LIVESTRONG is in a unique leadership position to develop solutions to alleviate the financial burden associated with cancer care.

It is also important to recognize that this study was completed during a time of intense political debate about national health care reform, including a Supreme Court case questioning the legality of the Affordable Care Act. Regardless of the Supreme Court’s decision, almost all policymakers agree that the health care system is in need of

²⁹ FASTCOMPANY, “Lance Won’t Blink” (October 2010), Available at: <http://www.fastcompany.com/magazine/150/can-livestrong-survive-lance.html>

improvement. Costs continue to increase, particularly in cancer care, and patients are asked to bear a higher percentage of costs. Given this perspective, political feasibility is important in considering these recommendations, but is not a key criterion. It is assumed that all parties agree that some degree of reform to the system is necessary; where they differ in opinion is how to implement these changes.

Criteria

The goal of this study was two-fold: 1) develop recommendations to target LIVESTRONG 's research about the practical concerns of survivorship, and 2) improve the effectiveness and impact of LIVESTRONG's navigation services. Correspondingly, my recommendations are separated into these two categories. Past research on patient-provider communication, medical decision-making, and cost-effectiveness precede this work.

All recommendations were evaluated using the criteria of minimizing implementation costs, maximizing collaboration and buy-in among stakeholders, and maximizing applicability to clients of diverse backgrounds. These criteria are specified below.

- Minimize implementation costs for LIVESTRONG and other cancer organizations. Recommendations should be cost-neutral in terms of financial and staff time requirements, and increase opportunities for partnership across organizations.
- Maximize collaboration and buy-in among stakeholders, particularly providers. If physicians and the broader cancer care team are not receptive to the recommendation, the program likely will not achieve its intended goals.
- Maximize applicability to clients of diverse backgrounds. LIVESTRONG services are available to anyone affected by cancer, and the foundation seeks to provide comprehensive assistance to the greatest number of individuals.

Recommendations: Further Research

1. **Conduct market research to develop a segmented approach to assist different client groups.** OOP costs are a universal challenge. However, different types of individuals (age, gender, race, socio-economic position, insurance type, etc.) access information in different ways. These groups likely have different coping strategies and varying comfort levels in discussing costs. The Medicare population in this study, for example, had limited experience using the Internet. This population also did not appear to be widely connected to the larger community of cancer survivors.
 - Emphasis should be placed on patients who report financial burden but did not initiate a discussion about costs. Future analyses should also focus on the timing of such conversations – why are patients unable to anticipate their financial burden?

- This alternative advances the third criterion of universality. By researching a diverse client population, **LIVESTRONG** will be able to target its services and provide as much value per dollar spent as possible.
- Given **LIVESTRONG**'s research infrastructure and expertise with multiple populations, this alternative would likely have low implementation costs, satisfying the second criterion.
- **LIVESTRONG** may have specific interest in young adults (age 15-39) and Hispanics, two groups where it has focused resources in the past. Providers may welcome this information, given that these groups are difficult to reach and typically underserved.

2. **Build an infrastructure of partners, professional standards, and political support that will advance the field of cancer navigation.** Since payers do not yet recognize these services for reimbursement, it will be important to demonstrate value for money and any associated cost savings. Any overlap or points of collaboration with other medical providers, including nurse practitioners, social workers, and medical financial counselors, should be carefully studied.

- Large-scale research studies are the foundation for this recommendation. **LIVESTRONG** could collaborate with its network of Survivorship Cancer Centers of Excellence, as well as government agencies such as the Center for Medicare and Medicaid Innovation (CMMI), to build on previous research that demonstrates the patient need and cost-effectiveness of navigation services.
- Continue to scale **LIVESTRONG**'s Navigation Services. **LIVESTRONG** can emerge as a thought leader by developing a training curriculum and partnering with other cancer organizations to train professionals in **LIVESTRONG**'s navigation model. By partnering with other organizations, this approach will incur minimal labor or infrastructure costs compared to other scaling options. The training curriculum could possibly be a source of revenue for **LIVESTRONG** in the long-term.
- All three criteria must be considered during the implementation of this recommendation.

Recommendations: Clinical Practice

3. **Improve tools that facilitate information sharing and increase ease of accessing financial assistance.** There are two types of applications for such tools: 1) direct access by patients and caregivers and 2) professional use by the cancer care team that works with patients, including social workers, financial counselors, and cancer navigators.

- Printed materials, including materials from the American Society of Clinical Oncologists (ASCO), the American Cancer Society (ACS), and CancerCare, provide suggested questions to facilitate a patient-provider conversation. Although these materials are widely distributed, it is

unclear whether they are effective in assisting patients with this delicate topic. This study suggests that there are many complicated factors that may impede this conversation. In-person coaching with decision aids could help.

- **LIVESTRONG** could initiate an awareness campaign, targeted at survivors, to emphasize the importance of initiating financial conversations early on in treatment.
- Existing online tools are often little more than a list of resources. This list varies on each cancer organization's website. The Cancer Financial Assistance Coalition (CFAC) attempts to pull together these resources on its website, creating a searchable database of financial resources. This tool could be improved so information is readily updated. A marketing campaign could assist in encouraging patients, caregivers, and cancer professionals to use this tool.
- This recommendation relies heavily on organizational collaboration. If online tools or printed collateral are proprietary to one organization and it is unwilling to share information, it will be difficult to expand the scope of this initiative.

4. **Develop a curriculum to share information on the financial impacts of cancer treatment at the clinical level, targeted at medical professionals.** Use **LIVESTRONG** Survivorship Centers of Excellence as a platform to develop targeted programs for physicians, social workers, financial counselors, and patient assistance organizations.

- This curriculum would focus on the communication between different members of a cancer care team, including primary care physicians, oncologists, financial specialists, and social workers.
- Research may be required to learn about existing programs and determine the best practice approach to this type of program. Care should be given to ensure applicability to a wide range of patients in the long-term. In the short-term, **LIVESTRONG** may want to focus on a specific patient population.
- Implementation costs may be high if a curriculum needs to be developed from scratch. However, the Survivorship Centers of Excellence provides a good starting point, as relationships are already established at the leading comprehensive cancer centers in the United States. Strong relationships also exist between **LIVESTRONG** and ASCO, and the annual ASCO conference could be a low resource-intensive opportunity to showcase a new program.

5. **Lobby for more accountability and transparency** about the cost of care, and consumer protection from prohibitive cost sharing, high interest health payment plans, or “wallet biopsy” software that might evade patient privacy laws.

- This recommendation may be the most challenging to implement, as fundamental changes need to be made in the US health care market. Many

of these topics are being considered as part of the Affordable Care Act. Currently, a lack of cost and outcome information prevents natural competition from flourishing. The best doctors are not necessarily rewarded as the most profitable doctors. Change will be gradual and any improvements will likely be in the long-term.

- Cancer patients are particularly susceptible to falling through the cracks in the health financing system – basic insurance is often not enough to cover the high costs of care. Many cancer patients, in this study and others, are willing to gamble with their savings in order to afford care. It will be important for **LIVESTRONG** to monitor new products and services (such as commercial payment plans or financial analysis software) that are targeted towards these patients to ensure that they are not being exploited.
- Providers, too, should understand this marketplace and be able to guide their patients towards well-informed choices.

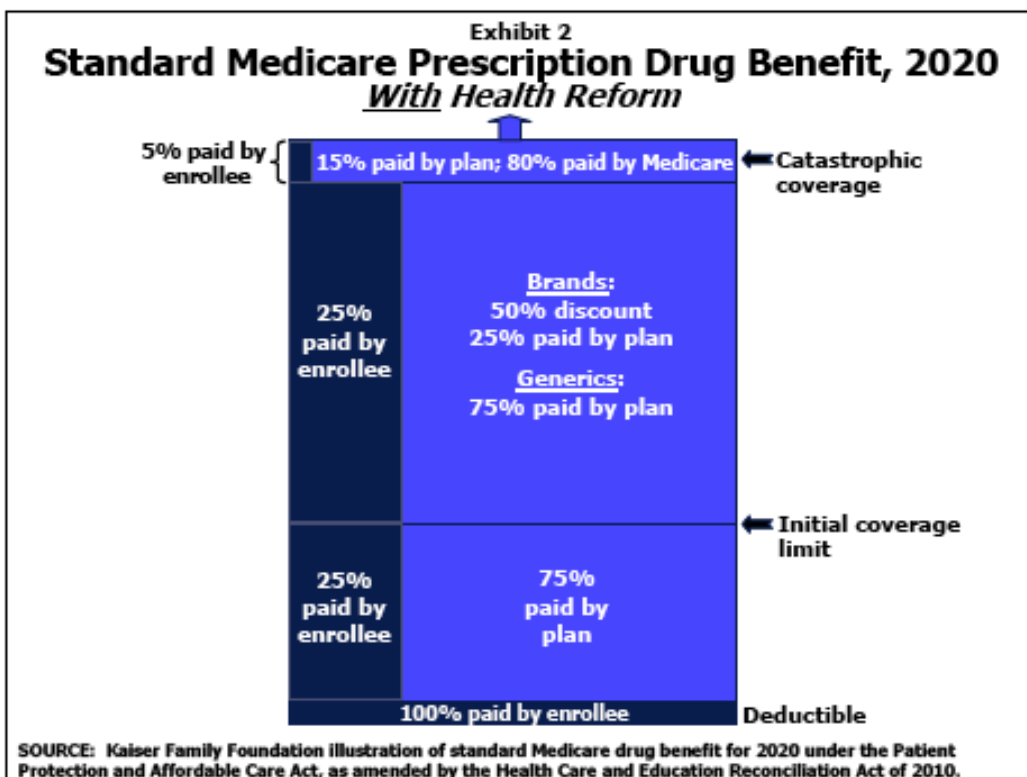
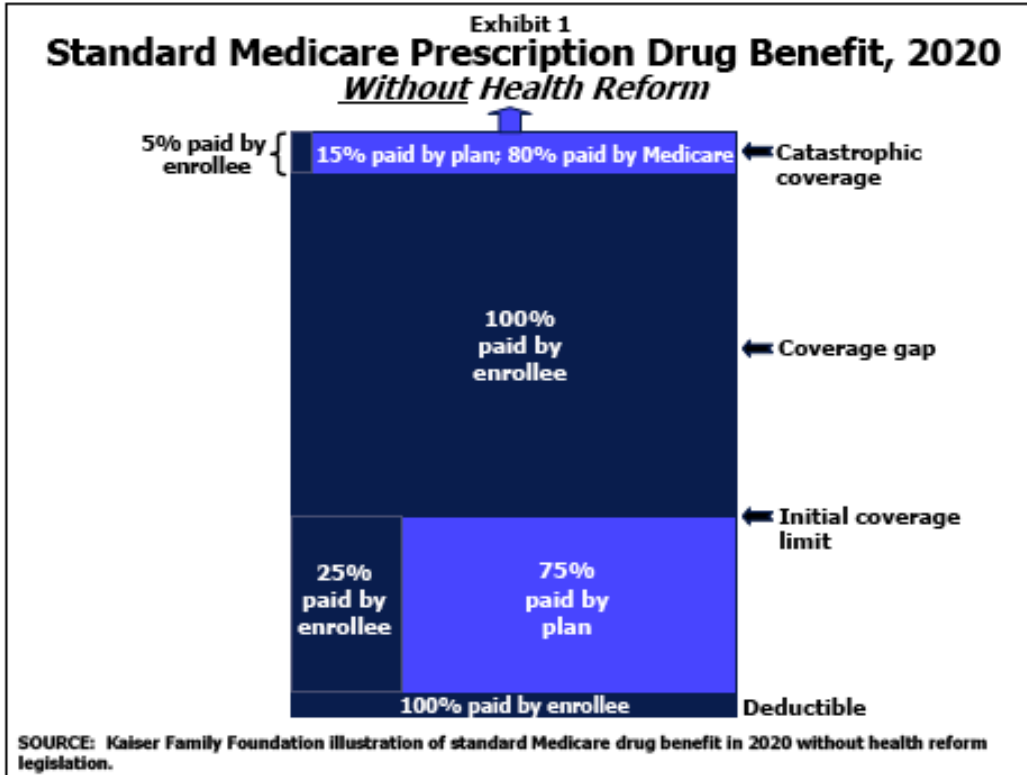
Conclusion

This study provides a nuanced understanding of the factors that impact the financial burden of cancer care for individual patients. My hypothesis was that early communication did not occur between patients and physicians about the cost of care – specifically, the individual burden related to OOP costs. These results suggest that communication may be happening, but that it is currently not helpful for many survivors. First, there is still too little communication overall, and it is mainly initiated by the patient. Only the most proactive patients appear to be seeking out this type of information. Second, communication is often too late. Patients will wait until they lose coverage or have other financial complications before trying to understand cost details relating to their treatment. Third, there are not sustainable solutions in terms of assistance – although help is available, it is highly variable and difficult to access. These conclusions suggest that national policy change could help with these systemic issues – validating the need for health care reform. However, given the deep partisan divides that exist, state and local solutions may be easier to implement.

These results suggest that a thorough needs assessment, as early as the first diagnosis, could help alleviate individual financial burden. Trained social workers or specialized patient navigators could help fill this role. Additionally, there appears to be an unmet need for more communication, not only between physicians and patients, but also between physicians, other care professionals, and the billing office. Compassion and transparency in information should be prioritized to empower patients to help themselves and to make better decisions about their treatment. As a global leader in the fight against cancer, **LIVESTRONG** is in a strong position to develop further research on this topic as well as pilot new clinical care models.

Appendix

Exhibits 1-2: Standard Medicare Prescription Drug Benefit, 2020, With and Without Healthcare Reform (Source: Kaiser Family Foundation, 2010)



Exhibits 3-4: Reductions in Cost Sharing for Brand-Name and Generic Drugs in the Medicare Part D Coverage Gap, 2010-2020 (Source: Kaiser Family Foundation, 2010)

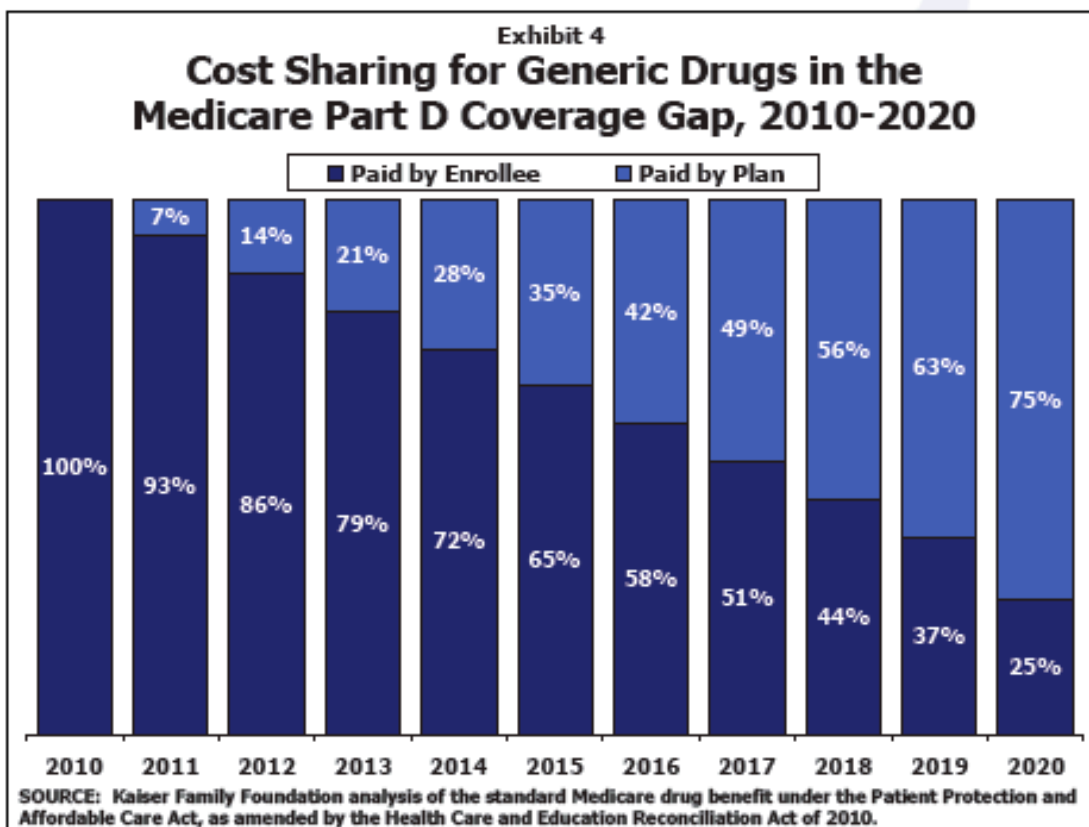
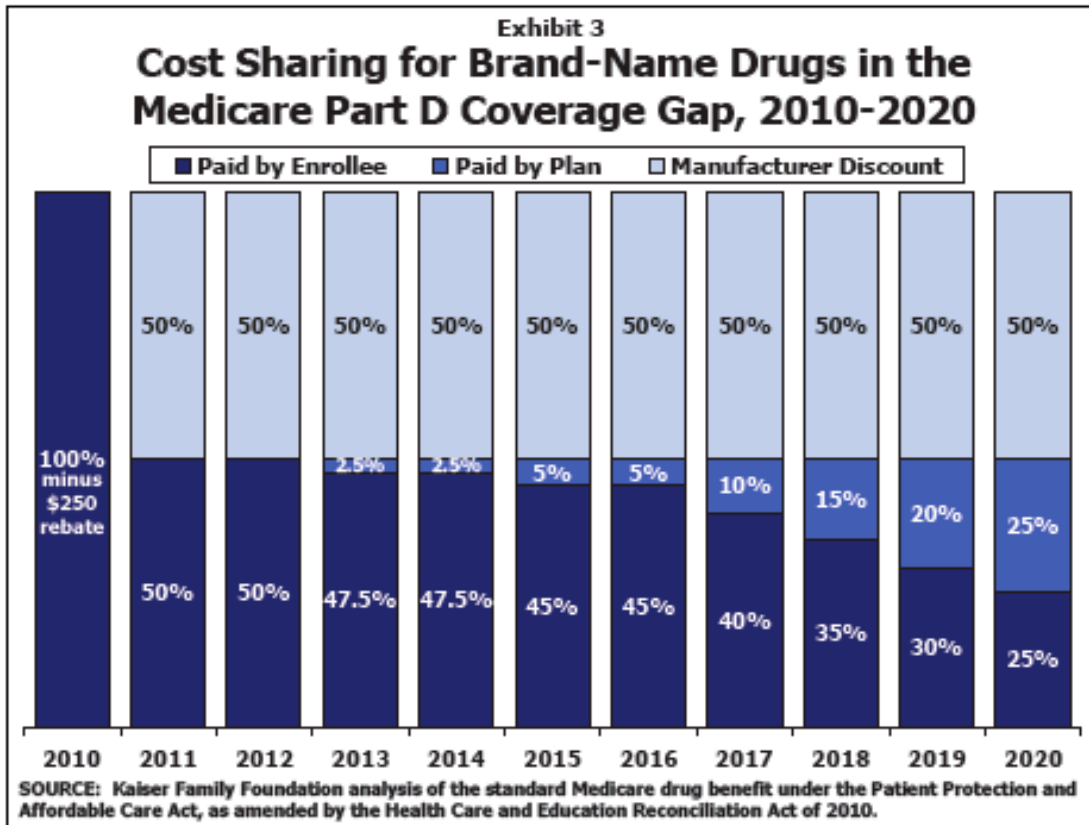


Exhibit 5: Types of costs incurred by Medicare cancer patients and caregivers

PATIENT:

Direct medical costs

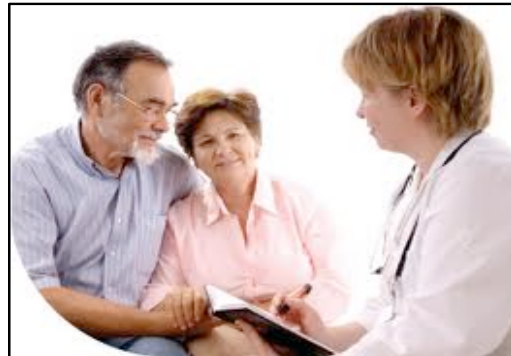
- Health insurance, medical services, prescription drugs, medical supplies

Direct nonmedical costs

- Transportation, lodging, meals, childcare, other costs attributable to treatment

Indirect nonmedical costs

- Loss of income and productivity, early retirement



CAREGIVER:

Indirect nonmedical costs

- Loss of income and productivity, transportation, meals, lodging

Exhibit 6: Members, Cancer Financial Assistance Coalition, 2012

- American Cancer Society
- CancerCare
- CancerCare Co-Pay Assistance Foundation
- Chronic Disease Fund
- HealthWell Foundation
- Leukemia & Lymphoma Society
- Leukemia & Lymphoma Society's Co-Pay Assistance Foundation
- Lymphoma Research Foundation
- The Max Foundation
- National Marrow Donor Program
- National Organization for Rare Diseases (NORD)
- Patient Access Network Foundation
- Patient Services Incorporated
- Sarcoma Alliance

Exhibit 7: Delivery Model, LIVESTRONG Navigation Services

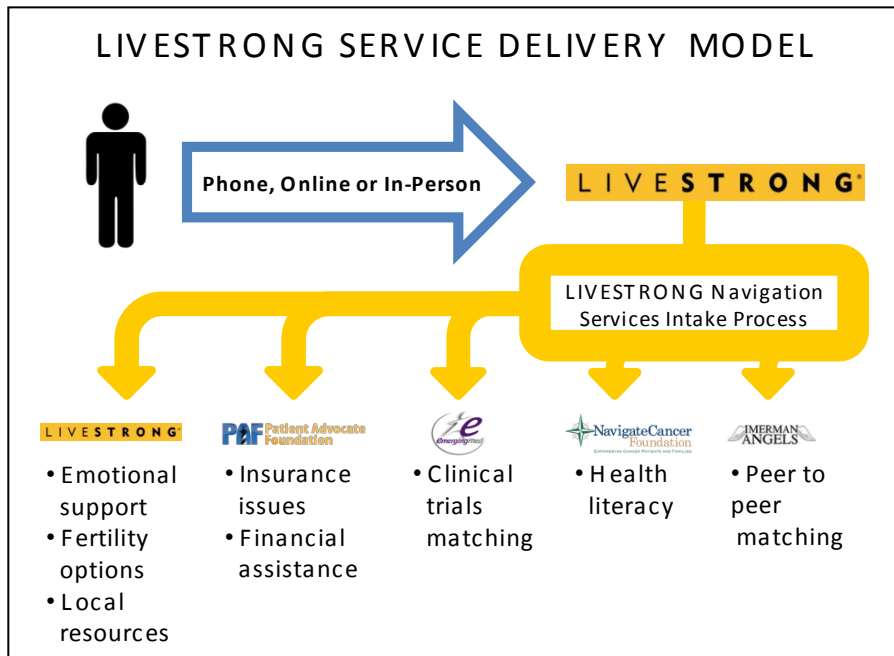


Exhibit 8: Age Distribution of Participants in Baseline Survey

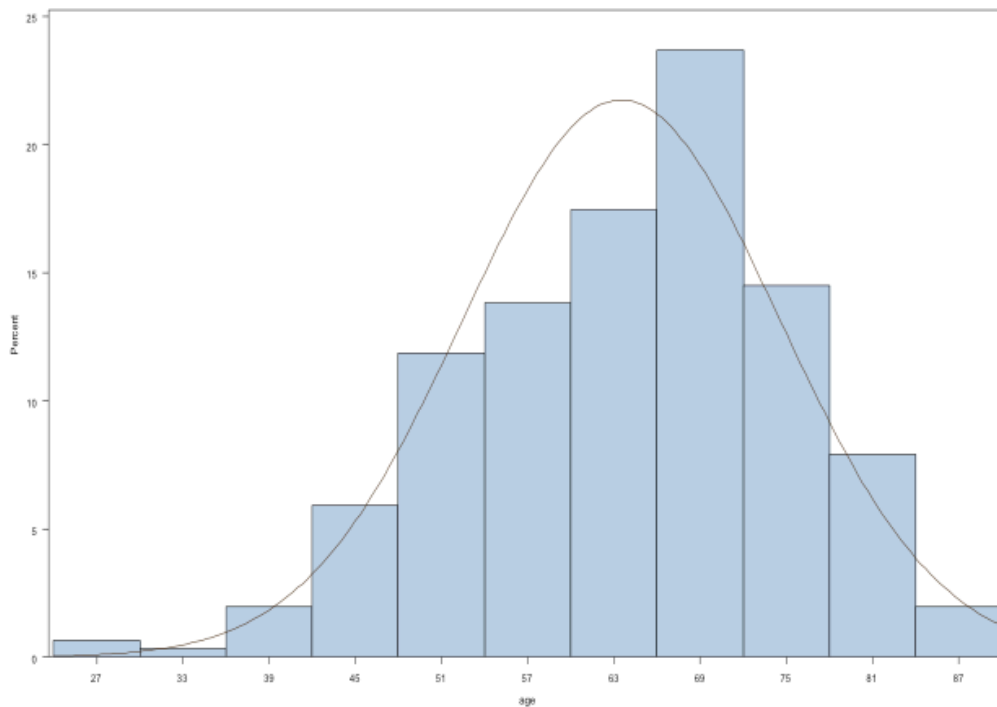


Exhibit 9: Race Distribution of Participants in Baseline Survey

Race	Count	Percent
African-American	40	13.0%
Asian	2	0.7%
Caucasian	243	79.2%
Other	10	3.3%
Unknown	12	3.9%
Total	307	100.0%

Exhibit 10: Annual Household Income of Participants in Baseline Survey, based on available data (“Prefer not to say” and “Unknown” are not included in this estimate)

Annual Household Income	Count	Percent
Less than \$20,000	87	28.3%
\$20,000 to \$39,999	110	35.8%
\$40,000 to \$59,999	36	11.7%
\$60,000 or greater	27	8.8%
Prefer not to say	36	11.7%
Unknown	11	3.6%
Total	307	100.0%

Exhibit 11: Select Hormone Therapies for Breast Cancer, Branded and Generic

Branded Name	Chemical Name	Generic Release Date
Arimidex	<i>Anastrozole</i>	June 2010
Aromasin	<i>Exemestane</i>	April 2011
Femara	<i>Letrozole</i>	July 2011

Exhibit 12: Interview Phone Script (IRB language removed in this version)

Phone Script for Patients

Caller: Hello, this is Jessica Harris from Duke University. May I please speak with _____?

Once Caller is speaking with participant:

Caller: Hello, my name is Jessica Harris. I’m a member of the research team with the Duke/HealthWell Foundation study, which you participated in a few months ago. I am

calling to follow up on a few of your responses. Our conversation will take about 30 minutes. Would you be willing to speak with me?

If participant is not willing (opt out):

Caller: I understand. Thank you for participating in the study, and have a good day.

If participant is willing:

Caller: Great! Our goal is to learn about your experience coping with the costs of your cancer treatment. Our hope is that your experience will help other patients with this challenge. Would you mind if I recorded our conversation?

CONVERSATION WITH DOCTOR

In response to the question, “Since your cancer diagnosis, have you had a discussion with your doctors about any difficulty in affording your cancer care?” you chose,

[YES]:

- Tell me about this conversation. How did the topic of costs come up?
- When in the course of your diagnosis and treatment did this conversation happen?
- Who initiated the conversation?
 - Would you have felt comfortable if your doctors had brought it up?
 - Would you have felt comfortable bringing it up yourself?
- What was it like to ask about this topic?
- What happened in result of this conversation?
- How responsive was your physician? Did he/she take it seriously? Did he/she change your treatment? Did he/she offer other resources or help?
- Is there anything that would have helped with this conversation? (eg, a list of topics to discuss, education on how to discuss costs with physicians, or education on available resources)
- Did you talk about the cost of care with anyone else? If so, how did you feel about it? Did anything happen as a result? How was it different than talking to your doctor?
- Have you tried to find help paying for your treatment? Where? What resources have helped “cushion the blow”?

[NO]

- Have you subsequently spoken to your doctor about the cost of your care? (If so, go to YES above)
- Why do you think you did not speak with your doctor about costs?
 - Would you have felt comfortable initiating this conversation?
 - Would you have felt comfortable if your doctor had brought this up?

- Is there anything that would have helped you have this conversation? (eg, a list of topics to discuss, education on how to discuss costs with physicians, or education on available resources)
- Did you discuss the cost of care with anyone else? If so, how did you feel about it? Did anything happen as a result?
- Have you tried to find help paying for your treatment? Where? What resources have helped “cushion the blow”?

-What, in your opinion, are the key issues surrounding communication about costs?

MEANS OF SUPPORT

- Who comes with you on your doctor visits (family, friends, caregiver, navigator, etc)? What do they do on your visits? Do they talk to your care team on your behalf?
- Do you talk to family or friends about the costs of your treatment?
- Do you talk to other professionals at the clinic, besides your doctors, about the costs of your treatment (nurse, social worker, financial counselor, navigator)? How do they help you?
- Do they provide emotional support? Personal organization? Understanding your treatment and medical information? Financial assistance?
- Does anyone provide this type of support for you? Do you need more support in this area?

COPING STRATEGIES

- You listed on the original survey several ways that you tried to make your treatment more affordable (eg, XYZ). Can you tell me more about what led you to pursue these options?
- Did your doctor give you different therapy options? Was cost a factor in your decision between these options? Why or why not?
- What were your priorities when discussing your care? (Effectiveness, time of treatment, disruption of routine, financial considerations, etc)

Caller: Thank you for talking with me! Your additional information is very helpful. Have a good day.

Questions for Additional Stakeholders

For physicians:

- Do you ever discuss costs with your patients? Under what circumstances do you/would you discuss costs?
- How do you broach this topic with your patients? Who brings it up?
- What is your relationship with your patients? Do you feel comfortable speaking to him/her?
- Under what conditions do you suggest alternative therapies for your patients based on costs?

For hospital administrators:

- Is cost information made available to physicians?
- Is cost information made available to patients?
- If you could make changes to the communication of costs to patients or physicians, what would you change about this process?
- Do physicians or patients often express concerns about cost of care to you? If so, what are their chief complaints or concerns?
- What, in your opinion, are the key issues surrounding communication about costs?

For navigators, financial counselors, and advocacy groups:

- What concerns do you hear from clients about financial burden?
- How do you broach the topic of treatment costs with your clients? Who brings it up?
- What resources have you found helpful to assist in this conversation? What resources do you use to provide next steps for your client?
- Do physicians or patients often express concerns about cost of care to you? If so, what are their chief complaints or concerns?
- What, in your opinion, are the key issues surrounding communication about costs?

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I could not have completed my data analysis without the assistance of Chantel Morey, Duke University Class of 2012, who transcribed several of my interviews. Chantel's maturity, hard work ethic, and curiosity contributed significantly to the research process. Finally, I want to thank my family and friends for being there throughout my MPP graduate experience. I could not have done it without their support.

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