



COST-OF-CARE CONVERSATIONS

An Annotated Bibliography



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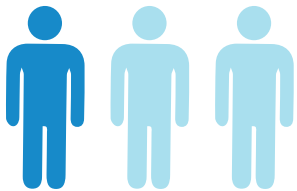
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Introduction/Background

In 2014, U.S. health care spending increased to reach \$3.0 trillion, or \$9,523 per person, comprising 17.4% of the overall share of the U.S. Economy. After the Affordable Care Act, in 2015, health care spending continued to rise to a total of 17.8% of the U.S. economy. Spending was allotted in the following manner: 32% hospital care, 20% physician and clinical services, 10% prescription drugs. This high health care expenditure poses both a societal as well as a patient burden. In 2015, 33% of sourcing was provided by private health insurance, 20% by Medicare, 17% by Medicaid, and 11% out-of-pocket spending.¹

This spending is unsustainable for the U.S. economy. Over the last decade, the U.S. has made several changes to the structure of health care, namely efforts to control health care spending. Despite attempt to change the structure of health care and its financial expenditures, many patients are paying significantly higher out-of-pocket expenses.² Due to the increase in higher out-of-pocket costs, nearly 1 in 3 Americans are financially burdened by their medical expenses.³ Moreover, this is not an isolated problem of the uninsured, in fact, 70% of Americans with medical debt have health insurance.⁴ These higher out-of-pocket expenses have been linked to lower quality of life, delayed or foregone health care, and an increased risk of adverse health outcomes.^{5,6,7} This burden has led a charge to promote more financial transparency and cost-of-care conversations between physician and patient, in hopes to affect the economic and fiscal sustainability of health care.⁸ Unfortunately, despite a nation-wide call to action, there remains a paucity of research on the incidence, receptivity, and outcomes of such conversations.

The aim of this study is to better understand the current literature of cost-of-care conversations to provide guidance for further research on improving the frequency and quality of cost-of-care conversations between clinicians and vulnerable patients.



1 in 3 Americans
are financially burdened by
their medical expenses

Methods

A literature review was conducted from the online database PubMed, accessed through the Department of Family Medicine at the University of Colorado Denver Anschutz Medical Campus. The initial search criteria “cost-of-care” yielded 2,773 articles. Meluch and Oglesby provided an historical systematic review of communication regarding patients’ healthcare costs that included numerous articles that were greater than 10 years old. Given the rapid changes in healthcare financing and access, we focused our review on the literature within the last 10 years.⁹

We narrowed the search to English language articles in the past 10 years. This yielded 982 articles, however, many articles were not relevant and when further reviewed with the additional filters of “conversation”, “patient-physician discussion”, and U.S. based studies, only 84 articles were identified. The abstracts were reviewed and further searches were completed based on relevant authors and references within other articles. Further investigation was completed using a search on Google for more possible types of literature on the subject. Final inclusion in this bibliography included 36 articles selected by the authors based on relevance.



36 articles

selected by the authors
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Results

After conducting the literature search and reviewing numerous articles, six broad rubrics to the current literature emerged. While many articles fell into multiple categories, we have grouped them based on the primary theme and findings. These six rubrics provide a structure to our ongoing study of cost of care conversations among vulnerable populations, and our training for providers, staff, and patients. Because care and treatment for cancer has undergone dramatic changes and rapid rise in costs over the past decade, many of the studies on cost-of-care conversations have been conducted in this population and clinical setting. A growing number of studies have more recently emerged in primary care settings and may be more relevant for a general review.

Incidence of cost-of-care conversations in clinical care

Barriers to cost-of-care conversations

Patient populations that are especially vulnerable to health care cost burden

Patient reception and attitudes towards cost-of-care conversations

Outcomes of cost-of-care conversations

How to conduct cost of care conversations

Incidence of cost-of-care conversations

Unfortunately, despite a nation-wide call to action, there remains a paucity of research on cost-of-care conversations. A literature search shows significant heterogeneity in the incidence rates of cost-of-care conversations, ranging from 14-65 percent^{10,11} values that are below, as well as interspersed within this literature review. Furthermore, the few papers that discuss cost-of-care conversations often point out factors associated with the incidence of these discussions include race gender, age, and income, as described below.

Ubel PA, Shang CJ, Hesson A, Davis JK, Kirby C, Barness J, Hunter WG. Study of Physician and Patient Communication Identifies Missed Opportunities to Help Reduce Patients' Out-Of-Pocket Spending. Health Affairs 2016. 35(4):654-661.¹²

Ubel et al. describe the cost of care conversations that occur in routine specialty care for chronic conditions that often require high cost testing, medications, and other treatments. Using audio recorded physician-patient clinical office encounters, the authors were able to identify the frequency of cost of care conversations, as well as the missed opportunities for conversations about cost of care and how patients might save money. This paper reports that frequently the physicians failed to fully engaged patient's financial concerns and often did not even acknowledge patient financial concerns. Physicians often relied on temporary solutions to cost concerns without making long-term plans for costly testing and treatments. However, many of these failures resulted from physicians' lack of knowledge about cost. The lack of price transparency coupled with wide variation in price represented a systemic barrier to more robust conversations about cost of care. Finally, Ubel et al. point out that for a health care market to function as a true market, physicians should be prepared to understand the costs of their prescribed testing and treatments, and help patients navigate their out-of-pocket expenses.

Hunter, W.G. et al. Patient-physician discussions about costs: definitions and impact on cost conversation incidence estimates. BMC Health Services Research. 2016; 16: 108.¹³

This article provides an in-depth review of the literature discussing the heterogeneity of reported incidence of cost-of-care conversations; this in and of itself is a novel component of this study as it provides a breadth of understanding and results of a breadth of current studies. They do so by completing an intensive literature review and summary of the incidence of cost-of-care conversations, most of which are within this annotated bibliography.

Furthermore, this team evaluated 1,000 visit transcripts from the Verilogue Point-of-Practice database to evaluate the nature of cost-of-care conversations within treatment for breast cancer, rheumatoid arthritis and major depressive disorder. They created a multidisciplinary team that involved physician researchers, medical students, undergraduate students, trained conversation analysts, graduate students training in public policy and marketing. The team evaluated the conversations and noted three broad definitions for cost-of-care conversations; 1: out-of-pocket costs (23% of the sample population), 2: cost/coverage discussions (out-of-pocket expenses as well as the insurance coverage of health care services, 30% of the sample population), and 3: cost of illness (any discussion of financial costs or insurance coverage broadly related to health or healthcare, 32% of the sample population).

What this study provides, primarily, is as stated above; a thorough literature review on cost-of-care conversations. However, aside from that, the study attempts to provide definitions for different cost-of-care conversations. This ultimately only points out that there will be a great deal of heterogeneity in the conversations that are had, given the fact that there is no current standard way to have these conversations, and furthermore, it might be difficult to do so.

Schmittiel, JA, et al. Patient-provider communication regarding drug costs in Medicare Part D beneficiaries with diabetes: a TRIAD Study. BMC Health Services Research. 2010; 10: 164.¹⁴

One significantly notable group of patients that could require a cost-of-care conversation, are those patients on Medicare. This is secondary to likely higher costs given more comorbid conditions, age, and income. This study focuses on patients that are specifically dealing with Medicare Part D and its cost driving medication and treatment plans. This study helps provide the upper limit of incidence predicted in the current research, whether this is due to patient population or other factors is unknown, however, it goes on to point out yet again, the heterogeneity of the incidence rates of cost-of-care conversations.

This research study evaluated the incidence of patient-physician conversations regarding medication costs, namely, patients with diabetes who reach the coverage gap in their Part D coverage. This information was obtained through the Translating Research into Action for Diabetes (TRIAD) study that was a multi-center study of diabetes care in managed care settings. The research study was conducted in a cross-sectional approach surveying 1,458 Medicare Part D beneficiaries (74% white and 54% female) from April-October 2007.

The participants were asked by survey if they 1: thought the issue of prescription drug costs was important enough to raise with a doctor, 2: if they wanted their doctor to consider the cost to them when choosing medication, 3: if they had talked with any doctor about the amount they had to pay for prescription drugs, 4: if their doctor had switched any prescription to a less expensive medication, and 5: if they had used any medication less often than the doctor prescribed due to the amount they had to pay. 44% of patients reported discussing drug costs with their physicians, while 76% reported wanting to have such discussions and 80% wanted their physician to consider costs when prescribing medications. Nearly half of the respondents reported that a physician had switched a medication to a less expensive version due to cost.

Females were more likely to report they wanted physicians to consider costs, and took medications less often than prescribed due to costs. Minorities were less likely to report having had a conversation with their physicians about cost. Patients 65-74 years of age were more likely to discuss drugs costs with their physicians and were also more likely to take less medication due to cost. Patients with lower incomes were more likely to think the issue of drug costs were important and more likely to have talked about prescription drug costs with their physicians.

Barriers to cost-of-care conversations

Effective doctor-patient communication is central in building a therapeutic doctor-patient relationship, which is important in the delivery of high-quality health care. Much patient dissatisfaction and many complaints are due to breakdown in the doctor-patient relationship. Noted problems in good doctor-patient communication, including cost-of-care conversations include: deterioration of doctors' communication skills, nondisclosure of information, doctors' avoidance behavior, discouragement of collaboration, and resistance by patients. Because of these barriers, many physicians report feeling uncomfortable and ill equipped to lead cost discussions.^{15,16} The following articles briefly discuss these barriers to cost-of-care conversations.

Altomare, I, et al. Physician Experience and Attitudes Toward Addressing the Cost of Cancer Care. Journal of Oncology Practice. 2016 12 (3), 281-288.¹⁷

This study is somewhat novel in that it aims to understand the attitudes of the physicians themselves in regards to discussing cost-of-care, and how they influence decision making and practice management.

The investigation consisted of a 15-question self-administered survey answered by a total of 333 oncologists. Most physicians, 60%, state that they often or frequently discuss cost-of-care with their patients. Of the physicians surveyed, they believed that initiation of discussion was evenly split between patient and provider. Despite this, 79-85% of physicians felt patients were not well informed, and surprised by the cost of their care. Furthermore, 77% felt that most patients do not understand the costs that society must pay for their treatment. In regards to the physicians' belief on their awareness of their patients' financial situation, 56% reported they felt confident they had an accurate sense of their patients' financial wellbeing.

Common barriers to the conversation that were discussed by the physicians included lack of resources/knowledge (58%), time (44%), "I can't help with cost-of-care" (32%), "nothing prevents me from discussing costs with my patients" (26%), "it's not my place to discuss cost-of-care" (17%), discomfort (17%), other (15%), and "discussing costs hurt the quality of care I deliver to my patients (6%)." (6%).

Physicians who reported having frequent conversations about cost-of-care were more likely to prioritize treatments in terms of costs, report understanding of their patients' financial well-being, and to feel that doctors should explain out-of-pocket costs. Interestingly, practitioners in academic settings were significantly less likely than community practitioners to discuss costs with their patients, however they were more likely to consider cost to the patient and to the government more than community providers.

These physician barriers to cost-of-care conversations reflect concerns that other studies have named, mainly, that the providers do not necessarily feel they have the resources or the knowledge base to have such conversations. Further studies will be needed to understand the best method to provide these resources to the physicians themselves in order to decrease the barriers to cost-of-care conversations.

Riggs, KR and Ubel, PA. Overcoming Barriers to Discussing Out-of-Pocket Costs With Patients. JAMA 2014; 174(6) 849-850.¹⁸

This article discusses possible barriers to discussion between physician and patient in regards to out-of-pocket expenses. These barriers, like the one above, often fall on lack of knowledge. The article points out the following possible barriers: 1: trading off less benefit for lower cost, 2: uncertainty about prices, 3: uncertainty about cost-sharing arrangements, and 4: uncertainty about future medical costs.

The authors point out that some physicians may have difficulty with the idea of cost-of-care discussions as they may feel that they are choosing less than the most effective care for their patients. However, they advise the physician consider a trade-off related to the cost-of-care reasonable if the physician would endorse the same trade-off in response to a strong patient preference not related to out-of-pocket costs. They point out that physicians often do not know the cost of medical services or medications. They believe this is often due to numerous prices for the same service, largely driven by insurer. They state that even when the physicians can determine the price of a specific medical intervention, the patient may still have a different out-of-pocket cost based on details of insurance coverage. Lastly, they state that because medical care is often unpredictable it is also difficult to discuss cost-of-care.

They recommend that providers engage the patient in the discussion of their care and seek better price information, which, in fact would likely be much more helpful if this technology was available, however, with the nuances of insurance, this could be a difficult process.

See comment in PubMed Commons below Patel MR, Shah KS, Shallcross ML. A qualitative study of physician perspectives of cost-related communication and patients' financial burden with managing chronic disease. BMC Health Serv Res. 2015 Nov 25;15:518.¹⁹

Patel and colleagues conducted a qualitative study to describe resident physician experiences with patients' financial burden. Their focus groups identified several major themes in including how financial burden becomes visible to or identified by the physician, the complexity of these conversations and difficulty navigating financial discussions, and the need for more generalizable tools for initiating cost-of-care conversations with patients. Finally, they call on researchers, clinicians, and policy makers to develop tools for helping physicians have cost-of-care conversations. This paper describes the interest in and ideas about cost-of-care among physicians developing early in training and the need to address the issue of cost among learners as well as practicing physicians.

Patient populations that are vulnerable to health care cost burden

Certain patient demographics are noted to be more “at-risk” for financial burden; these include families with lower incomes (at or below 250% of the federal poverty level), families with children 0-17 years of age, and the presence of a family member who was uninisured.³

Chronic diseases are at the forefront of etiological causes of our high health care expenditures. Diseases like Hepatitis C, can cost the U.S. a total of nearly \$6.5 billion dollars, while back pain is estimated to cost our society nearly \$41 billion annually. Other chronic disease like hypertension affect, 1 in every 3 Americans, and accounts for an expenditure of \$47 billion annually. Patients with diabetes account for 8% of American health care expenditures, totaling \$60 billion annual, while heart disease costs over \$100 billion a year. Arthritis, affecting one half of the U.S. population, accounts for \$74 billion and Chronic Obstructive Pulmonary Disease and Asthma, account for \$76 billion dollars a year. Mental health is considered to be an area in which more money could easily be spent, and yet, it already accounts for nearly \$83 billion in expenditures annually. Lastly, injuries and trauma, while possibly difficult to circumvent, account for \$92 billion of U.S. medical expenditures a year.^{20,21,22,23,24,25,26,27}

One significantly increasing aspect of health care is that of care for those with cancer. In fact, expenditures are 5%-11% of the overall US health care budget and are rising faster than many other sectors of medicine.²⁸ In total, cancer care costs approximately \$125 billion in 2010 and it's expected to rise to \$158 billion in 2020.²⁹ This societal burden has been spread among patients, with 25% of cancer patients with insurance report that they have used up all or most of their savings dealing cancer, and 33% reported a problem paying their cancer bills.³⁰ Furthermore, Medical bankruptcies are increasing, with those patients with cancer being twice as likely to file for bankruptcy as people without cancer, and younger patients appear to be particularly vulnerable to burdensome financial situations.³¹

Patel, M. R., and John R. C. Wheeler. Physician-Patient Communication on Cost and Affordability in Asthma Care. Who Wants to Talk about It and Who Is Actually Doing It. AnnalsATS. 2014; 11(10) 1538-1544.³²

As stated above, there are certain vulnerable populations to cost-burden. It is known that chronic diseases and their management can be cost restrictive. In order to better understand the discussions that are had with chronic disease this paper was selected.

The study participants were African American women with persistent asthma. The patients were recruited within the University of Michigan Health System through Blue Cross Blue Shield of Michigan and through the community. The study had a total of 422 patients (mean age 42.68, annual income less \$40,000). The participants were asked questions to target their 1: opinion on the importance of cost-of care conversations, 2: if they have had cost-of-care conversations with their physician, and 3: whether they feel costs are a problem or burden. Asthma control was measured. The patients also provided their out-of-pocket expenses related to medicine refills for asthma medication (mean total out-of-pocket expenses \$143.46 for one year with range of \$0-\$2,840). Lastly, the participants' charts were reviewed to measure the amount of urgent care visits (emergency rooms visits, urgent care visits, and hospitalizations over the last 12 months.

Within this group, 52% of participants had a perceived financial burden. Seventy-two percent reported a preference to discuss cost with their provider, while only 39% reported actually having a conversation with their physician about cost. Of the group of patients who have actually had the conversation with their provider, 76% of participants stated they initiated the conversation. Factors that were significantly associated with a preference to discuss cost of health care with a provider included: more out-of-pocket expenses, lower income, and lower asthma related quality of life. Factors that were significantly associated with discussion of cost with a physician included: older age, Medicare and government coverage, living longer with asthma, worse asthma control, more medications, more chronic conditions, lower asthma related quality of life, perception of financial burden and preference to discuss cost with a health care provider.

One other very interesting component of this study, and another reason why it was included, was that the researchers found that those who reported actually discussing affordability/cost with their doctor actually had worse asthma control and lower asthma related quality of life. Whether this is secondary to worsening disease, which yields more financial burden, or other factors was not completely researched, but could provide some information on groups to target to improve quality of health and possibly decrease financial burden.

Zafar SY, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patients' experience. Oncologist. 2013; 18(4):381-90.

Zafar et al. present results from a pilot study on out-of-pocket expenses among cancer patients.³³ Patients undergoing cancer treatment were surveyed at baseline and follow-up to determine the impact of health care costs on their treatment and well-being. Among insured patients, many sought financial assistance from a national copayment assistance foundation, and these patients seeking copayment assistance experienced considerable self-reported financial burden. Health insurance did not alleviate patients from the financial distress caused by cost of care.

Richman, I.B, and Brodie, M. A National study of burdensome health care costs among non-elderly Americans. BMC Health Services Research. 2014, 14:435.³⁴

This study targets a very specific subsector of the population that has yet to be investigated at length, namely, the patient population with ages 18-65. While this population of patients' likely experience fewer burdensome costs compared to those 65 and older, it does not mean that this population is immune to the financial burden of medical care.

The study group consisted of 5,493 participants obtained through the previous data collected by the Kaiser Family Foundation health tracking polls from March 2010-May 2012. Participants were 18-65, English and/or Spanish speaking and had access to a telephone. The study consisted of a telephone survey and the data were self-reported. The primary outcome variable of this cross-sectional study was participant-reported burdensome medical costs. To assess the participants, burden of health care costs the participants were asked "in the past 12 months, did you or another family member in your household have any problems paying medical bills or not?" Other information obtained included self-reported health status, income and health insurance type/status.

Results revealed that both younger (age 18-39) and older adults (age 40-65) struggled with medical cost-of-care burden. Younger adults tended to have lower income, as well as heavier reliance on Medicaid for health insurance or higher levels of uninsured status. These variables placed younger adults at a disadvantage and placed the group of patients at high risk for cost-of-care burden. Interestingly, while an income less than \$30,000 a year was associated with increased risk for burdensome health care costs, younger adults in the next income range, \$30-50,000, continued to have high levels of burdensome medical costs, while for middle-aged adults it fell (a 29-year-old earning \$30-50,000/year had an OR for burdensome health care that was 2.48 compared to those earning more than \$50,000/year, while an adult of 51, had an OR at the same income that was 1.40).

As possibly expected, middle-aged adults reported worse health status and when this population was subject to lack of health insurance the associated potential to be burdened by health care costs was much more significant than that for a younger adult (an uninsured 51 year old had an OR of 3.82 for burdensome costs compared to a peer with employer sponsored insurance, while an uninsured 29 year old patient by comparison had an OR of 2.61 for burdensome health care costs compared to a patient with employer sponsored insurance).

Overall, the study showed that lower incomes, lack of insurance and poor health all contribute to difficult paying for health care. However, how these risk factors affect different groups of people may be more important to study. As reported above, while younger adults are poorer, they are also less able to pay for care at higher salaries when compared to older adults. While this may be due to savings or more expenses are largely unknown. On the other hand, middle-aged adults are much more vulnerable to falls in health and are thus more vulnerable to periods of time in which they are uninsured.

Of note, the question asked during the survey did not ask about the patient specifically, but instead asked about the patients' household and thus may not, in fact, truly represent the target audience. Furthermore, the question asked about "difficulty" paying bills could have been interpreted in many ways, and there was no follow up question. However, the study does allude to some interesting interactions between economic vulnerabilities and age.

Patient reception and attitudes towards cost-of-care conversations

These days, our culture encourages patients to find a doctor who understands their needs best, and to seek out treatment that best suits them. Patients are becoming more autonomous and the once paternalistic health care model is now transitioning to a more patient centered model. One of the biggest questions in regards to cost-of-care conversations focuses on the attitudes and receptivity of the patients.

Kelly, R. J. et al. Patients and Physicians Can Discuss Costs of Cancer Treatment in the Clinic. Journal of Oncology Practice. 2015, 11(4) 308-313.³⁵

In this study, the researchers use a novel, in-clinic, web-based system, to provide a more thorough consultation in regards to the cost-of-care and the effect of treatment. This information seeks to better understand the likelihood of these discussions as well as their effects on the doctor-patient relationship.

The study included a total of 96 patients treated for metastatic breast, lung and colorectal cancer who were either on active treatment or surveillance. The study was completed from February to October 2013. A baseline questionnaire evaluating the patients need for cost of treatment information was provided prior to the clinical encounter. At the end of the encounter all providers were asked to discuss with their patient had any financial difficulties with their treatments to date. They did not receive formal training but were given a pre-scripted text. Treatment costs were provided to the patient by their oncologist during the consultation using the Web-based eVitalAdvisor oncology decision support platform. Both the patient and physician could see the costs, and the patients received an explanation that the costs shown were not their personal responsibility but rather the cost of drugs to the health care system and that costs did not take into account other considerations (facility feeds, co-pays for ancillary drugs, deductibles and other out-of-pocket expenses).

Eighteen oncology specialists were questioned about how often they discussed cost of treatments with patients. No physician said they always discussed costs with patients and only one admitted to frequently asking. Ten physicians (55%) reported they discuss costs a little, and three (17%) reported they sometimes discuss costs. Most notably, four providers (22%) reported that they never ask patients about cost of treatment. Of all providers, only five (28%) reported they felt comfortable having the conversations.

When it came to patients, over 80% of the respondents reported that it was important to know costs up front and that they had no negative feelings about having these conversations. Nearly three fourths (72%) of the patients reported that no health care professional had ever discussed costs with them for medical problems.

The most novel part of this study, the use of the in clinic decision making aid, was not fully investigated, which would have provided interesting research if compared to a provider having the same discussion without the decision making tool. Furthermore, the availability of the tool as well as the correctness of the tool was not completely evaluated.¹

Zafar SY, Chino F, Ubel PA, Rushing C, Samsa G, Altomare I, Nicolla J, Schrag D, Tulsy JA, Abernethy AP, Peppercorn JM. *The utility of cost discussions between patients with cancer and oncologists. Am J Manag Care. 2015 Sep;21(9):607-15.*³⁶

Zafar et al. surveyed patients undergoing cancer treatment. They found that while greater than 50% of the patients wanted their provider to discuss the costs of treatment with them, less than 20% reported any cost-of-care conversations with their physician. Greater than 50% of patients also wanted the physician to take into consideration the cost of treatment when making clinical care decisions. For the small number that did have cost-of-care conversations with their provider, 57% reported lower out-of-pocket costs. This paper describes the high level of patient interest in cost-of-care conversations even amongst patients suffering from cancer. It also reports on the success outcome of lower patient costs when these conversations do occur.

Danis, M., et al. *Exploring Public Attitudes Towards Approaches to Discussing Costs in the Clinical Encounter. Journal General Internal Medicine. 2013 July; 29(1): 223-9.*³⁷

This group explored the attitudes society may have towards physician-patient conversations about insurer and out-of-pocket costs. The group also investigates numerous communication strategies for broaching the topic that have been previously proposed by other authors but not researched in this issue to date.

The group recruited 211 participants to create 22 focus groups in Santa Monica, CA and Washington, DC from July-August 2011. The participants included a wide range of ages, ethnicities, education levels and salaries (mean age 48, 51% female, 34% African American, 27% Latino, and 50% with incomes below 300% of the federal poverty level). The participants all had health insurance. The focus groups were led by moderators that introduced a topic and then led participants through a series of scenarios involving treatment decisions and sample dialogue between patients and physicians. For all scenarios, participants discuss whether and how they would want their physicians to broach the topic of costs with them, and which treatment option they would ultimately choose. The participants also completed a self-administered questionnaire before and after focus group discussions.

The data concluded that in general, patient would like to discuss out-of-pocket costs. However, some barriers to communication were noted including doctors' visits being too impersonal for such conversations and physicians seeming too busy to discuss the costs of health care. Patients relayed that because of the rushed nature of many doctors' visits, the quality of the interaction was too low for meaningful conversation. On the other hand, while patients were generally comfortable with discussions on out-of-pocket costs, patients largely were not interested in discussing costs to insurers.

While patients may agree that physicians should play a role in reducing patients' out-of-pocket costs, as well as all costs, the patients felt that discussions on all costs were incompatible with their notion of the doctor's role. Older, sicker patients were more interested in having a cost-of-care conversation. White, Hispanic, and sicker participants were all more likely than other to agree with having their doctor consider out-of-pocket costs when making decisions.

The most novel aspect of this study was the investigation into the receptivity towards the discussion of costs. Overall, the attitudes held by participants in regards to discussing medical costs to society with physicians were more negative after the focus groups than beforehand. The focus groups reported that no approach that doctors took about talking about costs to society would make patient more receptive to the message. The one overarching theme that seemed to stand out was that long-term doctor-patient relationships and trust in the patient's physician would make the physician recommendations more acceptable.

This research implies a few interesting points which have been noted in other research studies as well; patients are receptive to discussions about out-of-pocket costs, but not societal costs. This often-replicated notion should be further explored in further research.

Irwin, B. et al. Patient Experience and Attitudes toward Addressing the Cost of Breast Cancer Care. The Oncologist 2014; 19: 1135-1140.³⁸

As stated above, cancer care is steadily increasing in price. This care, often a very emotional process, can become debilitating, not only in terms of physical side effects, but in financial side effects too.

The investigators distributed a self-administered survey aimed to address experience and preference of discussions of cost and views of cost control to patients presenting for a routine visit with their oncologist within 5 years of diagnosis.

The study consisted of 134 participants, most of whom were white, well-educated insured and married. Most respondents had an annual income of \$50,000 per year or higher and scored low on a financial distress scale. Most respondents also had local instead of metastatic cancer. The survey evaluated desired and actual timing and content of patient-physician discussions about costs, barrier to these discussion and views concerning methods of cost containment in cancer care.

Results revealed that the overwhelming majority, 94%, of patients wanted to discuss costs of care with their doctor and in this survey; only 14% reported having had such conversations. Patients felt uninformed about the cost of their care (67%) and many reported a surprise due to high costs (40%), a staggering 29% reported they did not understand the costs of their care. One-third of participants reported hardship because of their cancer care. Interestingly, in contrast to other studies, this investigation revealed that a greater majority of patients would prefer that physicians wait for the patient to initiate the conversation regarding cost-of-care or only initiate the conversation when a new treatment is being considered.

However, as previously reported in other studies, the patients herein were also consistently interested in discussing their out-of-pocket costs but were not interested in costs to insurers, 85% reported societal costs did not affect their decisions. However, 64% of patients reported they did not understand the cost to society. Participants with metastatic cancer were significantly less likely to want doctors consider societal costs (33% vs 6% of curable patients), and more likely to agree that society should pay for treatments even if they do not prolong life.

This study also focuses on patients' opinions of cost saving options that was not found in other studies. While most patients were concerned about the costs of care, when asked about cost decreasing strategies there was much heterogeneity in agreement as to which might succeed. Most respondents (58%) agree with generic substitution, but few endorsed preferential selections of drugs that prolong survival (15%), using more PAs and nurses (12%), paying doctors less (3%), greater means testing (9%), or greater cost sharing (3%).

Bullock, A.J., et al. Understanding Patients' Attitudes Toward Communication About the Cost of Cancer Care. Journal of Oncology Practice. 2012; 8(4) 50-58.³⁹

This study further explores the attitudes regarding cost-of-care conversations in patients receiving or having received cancer treatment. This was a cross-sectional descriptive study using a 31-question survey that included socioeconomic status, cancer diagnosis, health insurance coverage, personal experience with cancer treatment, communication preference, extent of cost burden related to cancer care, and influence of cost on medical decision making. The study population consisted of a total of 256 patients that returned questionnaires in the outpatient oncology unit at Beth Israel Deaconess Medical Center, during a 3-month period.

Results revealed that 59% of patient wanted to discuss out-of-pocket expenses with their physician and 76% were comfortable discussing these expenses with their physician, although a substantial minority (30%) would prefer to discuss costs with someone other than their physician. Twenty five percent of respondents agreed that paying for their cancer care was difficult, with 14% reporting a hardship. Nearly a third (29%) reported having to make sacrifices as a result of paying for their care. However, despite the financial burden of their care, most, 57%, did not consider out-of-pocket expenses in their decision making and 42% did not wish for their physician to consider such costs.

When it came to communication preferences, participants actively being treated with chemotherapy at the time of the survey administration were twice as likely to disagree with the statement "I would like my doctor to talk with me about my out-of-pocket costs when he/she recommends a cancer test or treatment". No other demographic factors were significant associated with communication preference (sex, ethnicity, education, income, employment or insurance status).

Like many other research studies discussing cancer treatment, this study also shows data that would seem to suggest that patients have a desire to understand out-of-pocket expenses, but that the patients themselves do not use out-of-pocket expenses as an influence to their medical decisions. Thus, physicians should be encouraged to have out-of-pocket expense conversations with their patients, and to address other concerns about time with the patient being an issue; this study reveals that a non-physician member of the oncology team, could also provide further information regarding out-of-pocket expenses.

Zafar SY, Abernethy AP. Financial toxicity, Part 1: A New Name for a Growing Problem. Oncology 2013. 27(2): 80-84.⁴⁰

"We don't travel; we don't do anything now because it's a \$100,000 illness." Zafar and Abernethy start off this brief introductory manuscript with a patient story about the financial strain of a serious illness, in this case, cancer. While this paper does not cover cost of care conversations per se, it is an excellent description of the financial burden carried by a growing number of patients. Their article title term "financial toxicity" brings into sharp focus the genuine hardships caused by the exorbitant cost of care. Many patients report feeling "caught between a rock and a hard spot," forced to choose between medical care and other basic needs like housing, food, utilities. This paper provides a brief introduction into the burden of cost of care for patients facing the burden of a serious illness.

Outcomes of cost-of-care conversations

The research seems to show that patients would like to have cost-of-care conversations with their providers, and that they tend to be receptive to these conversations. We will now discuss the impact of these conversations on patients' choices and physician decision-making.

Jung, O. S., et al. Out-of-Pocket Expenses and Treatment Choice for Men with Prostate Cancer. Urology. 2012 December; 80(6); 1252-1257.⁴¹

Like other oncologic processes, the cost-of-care can be burdensome for patients with prostate cancer. This research study aims to understand patient perceptions and influences on treatment of cost-of-care. This was a qualitative research study completed by the University of Pennsylvania. The study population was patients with localized prostate cancer treated within 6-18 months with surgery or external beam radiation. 41 patients (63% white, 71% with college education, and 58% with annual income of \$60,000 or more) enrolled in the study between Oct 2010 and Oct 2011. Trained interviewers were instructed to ask open-ended questions to understand the patient's knowledge of and attitudes about out-of-pocket expenses. Furthermore, patients were provided a questionnaire surveying the doctor's role in discussing out-of-pocket expenses. The median patient reported out-of-pocket expense over 12 months was \$640 (\$270-\$1,500).

Qualitative assessment revealed five major themes: 1: "My insurance takes care of it" (61%), 2: "Health is more important than cost" (51%), 3: "I didn't look into it" (34%), 4: "I can't afford it but would have chosen the same treatment" (22%), and 5: "It's not my doctors business" (17%). The majority (73%) reported they did not feel burdened by out-of-pocket expenses. Eighty percent of patients reported they "knew little" or "did not know" their likely out-of-pocket expenses before treatment. Similarly, 83% reported that out-of-pocket expenses did not affect their treatment choice. Most, 93%, reported that in retrospect they would have not chosen a different treatment had then know the actual cost of the treatment.

Of the few patients who did express burdensome out-of-pocket expenses, the majority were black (77%) and had less than college education (67%), earned an annual income less than \$60,000 (67%) and reported out-of-pocket expenses exceeding \$1,500. Despite feeling burdened by out-of-pocket expenses only 22% reported they would have chosen a different treatment had they known the actual out-of-pocket expenses.

While this study does point out some interesting perspectives of those with prostate cancer, the study is significantly limited by the overwhelmingly high socioeconomic status of the patients that could significantly influence the burden caused by out-of-pocket costs, and thus influence decision making in comparison to those of vulnerable populations.

Hunter, W.G, et al. What Strategies Do Physicians and Patients Discuss to Reduce Out-of-Pocket Costs? Analysis of Cost-Saving Strategies in 1,755 Outpatient Clinic Visits. Medical Decision Making. 2016; 36: 900-910.⁴²

This study is novel in that it investigates what strategies patients and physicians use in order to decrease costs. The study consisted of a retrospective analysis of audio-recorded patient-physician encounters. As in several other studies we identified, the patients in this study were from a database compiled by the Verilogue Point-of-Practice database. 1,755 outpatient encounters from an array of community practices treating patients with breast cancer, rheumatoid arthritis and depression between the years 2010-2014 were evaluated. Encounters were independently evaluated by at least 2 team members to measure the presence or absence of cost conversation, and if present, the initiator, the duration of the cost conversation, the intervention to which the cost conversation was related and the strategy for cost saving that was discussed.

Overall, 30% of conversations had a component of cost-of-care conversations, 58% of which were initiated by physicians. Of the encounters that included conversations about cost-of-care, 44% included discussion about cost saving strategies. In regards to cost saving strategies discussed, switching to a lower cost alternative therapy constituted 22% of the discussions, switching from a brand name drug to its generic constituted 7% of discussions, 5% of strategies consisted of changing dosage or frequency of intervention and stopping or withholding interventions constituted 4% of discussions.

Other strategies discussed consisted of interventions that did not involve the care plan itself. These consisted of strategies to change the logistics of care (changing the timing, source, or location of the patients' health care) 23 % of the time, while co-pay assistance or drug coupons constituted 21% of the discussions and free samples constituted 13% of the cost reducing strategies. A small percent (5%) of discussions included changing or adding insurance plans.

One barrier to the cost-of-care conversation has been the current economic drive for shorter, quicker, and more condensed physician visits. These visits provide a perception of insufficient time to discuss cost-of-care. The median visit length was 9 min 57 seconds. Encounters in which a cost saving strategy was discussed, the discussion itself lasted a median of 68 seconds, with 53% lasting longer than 1 minute. While a 68 second discussion may seem insufficient, when considered that this is 10% of the office visit time, this could lead to much more limitations for the discussion itself.

How to conduct cost-of-care conversations.

As stated above, the health care expenditures of the U.S. are growing at an alarming rate. Medical professionalism requires the wise management of resources as well as the protection of patients from financial burden. A provider should discuss with patients the true necessity of procedures, tests, and treatments. While there has been a growing interest in how to discuss cost-of-care with patients, there has not been much written about how to go about these conversations.

In 2012 the American Board of Internal Medicine Foundation, Consumer Reports, and nine medical specialty societies launched the Choosing Wisely campaign. Choosing Wisely is an example of a successful application of the research on cost-of-care conversation. While grounded more in clinical shared-decision-making Choosing Wisely has an important element of cost-of-care and serves as a potential starting point for clinicians interested in having cost-of-care conversations with their patients. While this campaign was not necessarily the first of its kind, it was well received, and most certainly was a substantial driving force to the commencement of physician and patient cost-of-care conversations.

Hardee JT, Platt FW, Kasper IK. Discussing Health Care Costs with Patients: An Opportunity for Empathic Communication. J Gen Intern Med 2005. 20:666-669.⁴³

In this early study from 2005, Hardee and associates offer an introduction to cost-of-care conversations that uses advanced communication as a tool for providers. Their paper outlines an approach that, first, gives permission to providers to ask about the impact of cost, and then encourages providers to incorporate several elements of empathic communication to build an alliance with the patient, share in their concern about costs, and address these concerns directly. They point out it is also essential for providers to know about local resources that can help alleviate some financial burdens. This brief manuscript offers a terrific introduction for providers and their staff members to understand the underlying concepts of difficult conversations.

Schiavoni KH, Lehmann LS, Guan W, Rosenthal M, Sequist TD, Chien AT How Primary Care Physicians Integrate Price Information into Clinical Decision-Making. Journal of General Internal Medicine 2017. 32(1): 81-87.⁴⁴

This innovative study placed price information in the electronic health record at the point of care for commonly ordered tests and procedures (e.g., blood tests, x-rays, CTs, MRIs). Physicians were then interviewed about their "gut reaction" to this information being presented right at the time of entering the test order. They were also asked if and how they incorporated this cost information into their clinical decision making and how they included patients in their decision. Physicians reported that when they knew cost might be a burden, they were able to use the cost information to engage patients in a cost-of-care conversation. They also reported their belief that it was primarily the physician member of the care team's responsibility to have these cost-of-care conversations with the patient. This paper describes a systematic method for delivering price information to physicians at the point of care and how this was well accepted by the physicians and helped initiate cost-of-care conversations.

Wolfson, D., et al. Engaging Physicians and Consumers in Conversations About Treatment Overuse and Waste: A Short History of the Choosing Wisely Campaign. Academic medicine. 2015; 89(7)990-995.⁴⁵

This article further details the history and purpose of the campaign. Per the authors, the origins of the campaign date back to 200. The campaign appears to have stemmed from a charter that provided a new set of professional responsibilities that physicians were to uphold.⁴⁶ The three core principles of the charter were, 1: primacy of patient welfare, 2: patient autonomy, and 3: social justice. The campaign itself was to be focused on supporting conversations between patients and physicians about what care is truly necessary.

Unfortunately, physician's aspirations and actions in regards to management of health care spending are often not equal. While 90% of physicians aspire to provide more fair distribution of financial resources and improve professional self-regulation, they, in fact, would accommodate a patient who badly wanted a test 36% of the time, even if it was unnecessary.⁴⁷ The Choosing Wisely campaign was initiated to help bridge the gap between the aspirations and actions of physicians.

In 2009, a committee of consultants gathered to explore the language physicians used to describe their ideals towards medical professionalism and the principle of "just distribution of finite resources". For this research, the group conducted interviews, focus groups and a national survey which found that the primary driver for physicians is 1: patient well-being, 2: personal and professional well-being of the physician and 3: improved quality of care for patients. When physicians were presented with language that moved away from the interests of their patients, or their own well-being, and towards society's needs they were less motivated to take action. Thus, a call to action was made to continue to promote health justice and professional integrity.

Following the call to action, the National Physicians Alliance (NPA) received a grant to develop "five things to question" that ultimately provided the framework for the Choosing Wisely campaign. The NPA created a list of five interventions in internal/family medicine and pediatrics that should not be performed as part of their Good Stewardship Project. At the same time, the University of Texas at Galveston asked specialty societies to identify tests and procedures as a way for physicians to constructively address the cost and waste issue in medicine. Ultimately, more than 50 specialty societies have participated in providing recommendations.

The Consumer Reports was asked to come on board, given their long-standing history of mission of focused health care. It was thought that they could help to provide the recommendations to the public in a way that empowered patients to understand the recommendations and engage in conversations with their providers. Consumer Reports completed a survey demonstrating that large numbers of consumers were undergoing wasteful heart disease screening tests, while rarely receiving effective explanation from physicians as to why they were having the tests done. The survey focused on 1183 Consumer Reports subscribers, 40-60 years of age, who did not have hyperlipidemia or hypertension, never diagnosed with any heart condition, never a smoker, rated their health "good" or "excellent". Of that group, 39% had had an EKG in the last five years, 12% a stress test, 10% an ECHO. Sadly, only 17% of participants understood what problem the test was screening for.^{48,49}

Soon after this research, the Consumer Reports, the ABIMF and the ACP worked together to make the recommendations provided in the Choosing Wisely Campaign and translated them into recommendations for consumer-friendly briefs.

Unfortunately, despite the charge by the Choosing Wisely campaign, evidence has shown that there continues to be a deficiency in the amount of cost-of-care conversations had between physicians and patients.

Conclusion

The United States continues to struggle with unsustainable health care costs. As we continue to tackle these burdens it will become imperative that our physicians continue to be diligent in decreasing areas of overuse attempting to educate patients about the societal costs of care, and most notably, continuing to have and also increasing the frequency of, cost-of-care conversations. Several examples of how to initiate and conduct these sometimes difficult cost of care conversations have been published and serve as excellent starting points for providers and office staff.

The research above clearly shows that patients would be receptive to having cost-of-care conversations. These conversations are perceived as difficult by physicians as well as patients. This could be secondary to lack of knowledge as well as lack of time in our ever- growing schedules as physicians.

It will be important that physicians continue to broaden their knowledge of costs and resources that may be used to help offset these burdens.^{50,51,52} It may be potentially beneficial to provide a more robust approach with universal screening for financial harm, adopting a more universal approach, understanding financial ramifications and value recommendations and optimizing care plans for individual patients to build more shared decision making.^{53,54}

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