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Financial Distress in Cancer Patients

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Abstract

Novel diagnostic and therapeutic options offer hope to cancer patients with both localized and advanced disease. However, many of these treatments are often costly and even well-insured patients can face high out-of-pocket costs. Families may also be at risk of financial distress due to lost wages and other treatment-related expenses. Research is needed to measure and characterize financial distress in cancer patients and understand how it affects their quality of life. In addition, health care providers need to be trained to counsel patients and their families so they can make patient-centered treatment decisions that reflect their preferences and values.

Background

Advances in translational research have lead to new options for cancer patients, including the introduction of new chemotherapy and targeted agents, imaging and surgical techniques. However, this new technology comes at a high price tag. In 2010, three of the top 10 drugs administered in the outpatient setting were cancer treatments, including rituximab ($1.3 billion), bevacizumab ($1.1 billion), pemetrexed ($394 million) and docetaxel ($387 million).[1] Also, the top 10 average annual per beneficiary cost of each drug in Medicare part B included three other cancer drugs: cetuximab (at a cost of $25,898 per beneficiary), trastuzumab ($25,797), and bortezomib ($19,667)[1]. These newer cancer drugs, while potentially more effective and with better (but not harmless) toxicity profiles, can also cost significantly more than older ones [2]. This has raised questions about whether the benefit is worth their high cost[3], if the prices are justifiable, and if the costs are sustainable for patients and their families[4]. At the same time, out-of-pocket costs for patients have risen at a much faster rate than health plan costs. Insurance plan benefits can vary widely, ranging from a fixed co-payment to a percentage of the medication's cost. Given the high cost of these drugs, even well-insured patients can face high co-payments. As a result, patients are faced with balancing potential benefits of treatments against both their economic and physical toxicity.

Definition of financial stress

Many terms have been used to describe patients' feelings about their financial condition[5], including perceived economic well-being,[6, 7] personal financial wellness, [8] financial satisfaction[9, 10], perceived income adequacy,[11] financial strain,[12] financial stress,[13–15] debt stress,[16] economic strain,[17] economic distress.[18, 19] In the oncology literature, distress, burden and toxicity are often used as synonyms. As a way to quantify the term, financial burden has been defined and used in some studies as the ratio of health-related spending (out-of-pocket costs) to household income.[20–24] For example, in one study using Medical Expenditures Survey data, high total burden was defined as health care costs (including

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premiums) exceeding 20% of pre-tax family income.[24] Among cancer patients, 13.4% of non-elderly adults with cancer had high total burden, in comparison with 9.7% of those with other chronic conditions and 4.4% of those without chronic conditions. These figures were drawn from 2001–2008 data; given the rising costs associated rising costs associated with advances in cancer treatment, it is likely that these numbers have increased in recent years.

Role of cost sharing

The purpose of cost sharing is to reduce "moral hazard" which is the economic principle that encourages well-insured patients to overuse healthcare services because they do not bear the full burden of the cost. Cost sharing places patients "at risk" for a portion of their health care expenses through deductibles, co-payments, co-insurance or "caps" on benefits. The RAND Health Insurance Experiment (HIE) found that families randomized to high deductible insurance plans used up to 30% fewer services compared to those who received free care, with reductions noted across all income groups.[25–27] In the three decades since the RAND HIE, numerous observational studies have found that increased cost sharing is correlated with reductions in medical care use.[25]

Although the overall health status of most patients in the RAND HIE was not affected, the reduction in utilization was harmful among the sickest and poorest patients, despite reduced cost sharing for low-income families.[26, 27] Studies of prescription drugs have found that their utilization is sensitive to co-payment changes. Doubling drug co-payments was associated with reduced utilization of discretionary medications (non steroidal anti-inflammatory drugs 45%; antihistamines 31%), but also decreased use of effective medications for serious chronic diseases (antidepressants 26%, antiasthmatics 32%, antihypertensives 26%).[28] Medicare beneficiaries with annual "caps" on their pharmacy benefits were also noted to have worse clinical outcomes for chronic illnesses such as diabetes, hypertension, and hyperlipidemia.[29]

Cancer patients' out-of-pocket costs

There are limited studies on the impact of cost sharing on cancer patient treatment and outcomes. A study of Medicare patients found that women with employer-sponsored supplemental insurance were more likely to undergo screening mammography than women without any supplemental coverage (OR 3.03 95% CI 2.17 to 4.23), a disparity attributed to the high levels cost sharing associated with mammography for women with Medicare coverage alone.[30] An analysis of a insurance claims found that patients with early stage breast cancer who face high co-payments for adjuvant hormonal therapy are less likely to be compliant with therapy.[31] Other investigators have also found similar associations between higher co-payments and lower compliance with anti-cancer drugs. [32] Other studies have also found that high co-payments may affect treatment choices and other decisions. In a group of cancer patients given hypothetical scenarios, patients were less likely to pay high co-payments for treatments of modest benefits. In the palliative setting, socioeconomic status (employment status, income) were predictive of a lower willingness to pay.[33] Most recently, a study of 254 American patients seeking help from a national co-payment assistance foundation in which 42% reported significant or catastrophic financial burden, 46% reported spending food and clothing and 20% reporting taking less than the prescribed number of pills.[34]

These costs can be catastrophic for families. A study of bankruptcy claims in 2007 found that 62% were due to medical bills. Consistent with other definitions of financial hardship and strain, most of these bankruptcies occurred mainly patients who were traditionally considered middle class (well-educated and homeowners).[35] Cancer patients may be at particular risk. A study which linked Washington State SEER registry with Western District of Washington bankruptcy court records between 1995 and 2009 found that bankruptcy filings were 2.65 higher among cancer patients than non-cancer patients. This effect was seen across cancer types. Younger cancer patients were two to five times more likely than cancer patients over 65 to file for bankruptcy, suggesting that Medicare and Social Security may reduce the bankruptcy risk among older patients.[36]

The challenges ahead

Several studies have reported that patients report wanting to be given accurate and realistic information about their treatment options,[37] which should include cost. A cross sectional study of the Australian general population found that respondents wanted to be told about expensive anti-cancer drugs, even if they were unlikely to be able to afford the medications.[38] Another study of 256 cancer patients in the U.S. found that 76% were comfortable discussing costs with their physician. However 57% reported that they did not consider out-of-pocket costs when making treatment decisions and 42% did not want their physicians to consider these costs.[39] Therefore, although cancer patients may be willing to discuss costs with their medical team, it is unclear how these patients seek to use this information. Notably, this may differ from the non-oncologic population; focus groups of non-cancer patients expressed that patients did not want to talk about cost, and resented it when it was brought up.[40]

Furthermore, the American Society of Clinical Oncology’s Cost of Cancer Care Task Force Framework Statement proposes that “patients should be empowered to discuss cost with their oncology healthcare teams and access resources to help with costly therapies.”[41] However, physicians and other health care providers need guidance on how to empower patients to make these decisions as well as on how to communicate about these costs and a better understanding of how these costs impact quality of life.

Measuring financial toxicity and quality of life

Despite the increasing discussion about the cost of care, there is little information about the long-term financial effects of cancer treatment on patients and their families. Cancer patients may benefit from increased information or guidance regarding out-of-pocket costs. Along this line, research on methods to examine the patient's subjective and objective financial burden is essential for optimal decision making.[42] Financial burden may be associated with, if not predictive of, other markers of distress in cancer patients. One study of advanced cancer patients in early-phase clinical trials measured employment status, unexpected medical costs, concerns regarding wages (e.g. termination, use of sick time) and financial stress, as well as depression, anxiety, quality-of-life, and global health. Patients with medical costs concerns had poorer quality-of-life outcomes over time, suggesting that financial burden may be negatively associated with quality-of-life..[43]

Research in this field is challenging because there are no validated instruments that quantitatively measures how the financial burden patient undergo with their quality of life. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30),[44] a prominent QoL instrument with a main focus on cancer patients developed in 1993, does include one item that qualitatively assesses financial impact of the disease (“*Has your physical condition or medical treatment caused you financial difficulties?*”). Another instrument, The InCharge Financial Distress/Financial Well-Being Scale (IFDFWS) is an 8-item self-report measure of current, subjective financial distress/financial well-being[5] in the general population. Although a possible proxy of financial well-being, the IFDFWS is a brief framework to evaluate the general population’s reactions to their financial situation. However, it does not measure financial well-being and quality-of-life as a result of a specific outside stressor, nor does it integrate any quality-of-life assessments. In addition, it has also not been prospectively evaluated in patients who are facing cancer or other life-threatening conditions. Validated instruments to quantitatively assess the financial burden of cancer and how it affects patient's quality-of-life are urgently needed.

Communication of costs

Research on patient-physician communication has largely focused on communication of treatment and prognosis,[37, 45] and there is limited information on financial concerns, particularly in oncology.[46] Given the significant out-of-pocket costs and financial risk many patients face, like all "bad news," communication about this critical topic needs to be better integrated into clinical care. Since economic burden of cancer treatment can clearly have a catastrophic effect on a patient and family's financial stability, we believe that economic toxicities are as important as physical ones, and patients should be well counseled.

Research is needed to determine how patients should best communicate these cost-related concerns with their health care providers. There is little information on how patients choose to communicate about costs with their health care provider, who should initiate these conversations, or even if the medical provider should be the one initiating it. Oncologists themselves vary in their comfort in discussing this issue with their patients.[47] Like all aspects in health care, health care practitioners need to be trained to counsel patients in a patient-centered manner that helps patients make treatment decisions that reflect their preferences and values. Rigorous studies need to be conducted to understand how this information should be best communicated, which care providers should be conduct them (physicians, nurses, social workers) and if any decision aids or educational materials may help patients address these challenging issues.

Conclusion

Patients and their families will likely continue to see high out-of-pocket costs as cancer costs rise and payors shift cost to patients. Research is needed to help clinicians understand the extent of "financial toxicity" these costs cause. In addition, health care providers, including physicians, nurses and social workers need to be trained to how to address cost related concerns with patients and their families. This information will be critical in helping patients make value-based, preference-sensitive decisions.

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