Let’s Talk About Financial Toxicities

Anne Katz, PhD, RN, FAAN

We should care about quality of life, and the costs of treatment very much influence quality of life—not just for patients, but for their family members as well.

I have attended a number of conferences in the past few months that have included excellent sessions about precision medicine, targeted therapies, and personalized medicine. These terms may be confusing, and the generic names of the various drugs—not to mention the trade names—present some unique challenges. I do not work with patients who are taking many of these drugs, so I often lump them together in my mind as mibs and mabs. I am in awe at the ability of my oncology care provider colleagues to not only pronounce the names, but also remember their various mechanisms of action and side effects.

Increasingly, we are seeing articles published in journals that explain these drugs, including some very helpful pieces in the December 2017 issue of our sister journal, the Clinical Journal of Oncology Nursing. However, also included in the December issue was an interesting overview of the financial toxicities associated with cancer care (Fessele, 2017). There has been a lot published on this topic recently, including a position statement by the American Society of Clinical Oncology (2017) that calls for solutions to address the affordability of cancer drugs while considering the effects of financial harm to the patient balanced with the value of high-risk, high-reward science to the developers and manufacturers.

The article and the position statement brought my thoughts back to the presentations I attended. While marveling at the ability of presenters to pronounce drug names and list their many and varied side effects, I was also struck by the absence of any discussion about how much these drugs cost. Audience members sitting around me nodded their heads when a medication in these classes was discussed. I overheard two nurses sitting in front of me talking about the response of the patients they had cared for and the almost miraculous change in their conditions. One of the nurses pointed out that she witnessed unusual side effects and noted how challenging it was to figure out if the side effects were related to the medication or to something else. The cost of the medication was not mentioned, but perhaps this is not part of nursing care. Or is it?

The research on this topic is interesting. In one study (Kaur et al., 2016), 38% of patients with advanced cancer were concerned about the costs of their care and the burden on their family. In another study (Bullock, Hofstatter, Yushak, & Buss, 2012), 68% wanted to know the out-of-pocket costs of their treatment, but 57% did not consider this in their treatment decision making. This appears to be a common theme, with 81% of patients with financial concerns in another study (Meisenberg et al., 2015) not wanting personal costs to be a consideration in their treatment plan but 28% saying they would be willing to receive less expensive treatment of equal effectiveness. Discussions about the cost of treatment occur less than half of the time, are more often initiated by the patient than the oncologist (61% versus 38%), and are not long in duration (median time = 35 seconds), with younger adult patients more likely to ask about costs (Hamel et al., 2016).

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The risks contributing to financial problems include the patient and family members having to leave their employment or reduce their hours of work, as well as invisible costs, such as parking for clinic visits. Having to declare personal bankruptcy may be the eventual outcome of loss of income, not to mention that some patients have to choose between buying food or paying for out-of-pocket costs of treatment. The consequences of the financial toxicities of treatment are well known, including issues with adherence and treatment delay.

I feel strongly that we, as nurses, need to discuss this with our patients. We care for the whole patient. This, in my opinion, is what makes oncology nursing so satisfying. We should care about quality of life, and the costs of treatment very much influence quality of life—not just for patients, but for their family members as well. A simple question, such as “Are you able to afford this medication/co-payments?” or “Has your treatment affected your or your family’s financial situation?” opens the door for us to be advocates for our patients. It allows us to refer patients to assistance programs, social workers, financial counselors, and other resources. It is not an easy conversation to have, but nurses have difficult conversations with patients all of the time. The Oncology Nursing Society has a useful toolkit that addresses these issues (https://bit.ly/2zN8NMI) and includes helpful information about when and how to start the conversation, as well as resources for patients.

However, I also think that we need to go beyond the individual patient and broaden our discussion during tumor boards, nursing and grand rounds, and conference presentations. Each and every time we discuss a new medication, we need to know what it costs, if it is covered by Medicare or insurance, and the out-of-pocket costs to the patient associated with the treatment, such as more frequent visits to the clinic, parking, lost wages, and supportive medications to treat side effects. We talk about all of the other toxicities; therefore, we must talk about financial toxicities too.

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REFERENCES