



Out-of-Pocket Cancer Care Costs and Value Frameworks: A Case Study in a Community Oncology Practice with a Financial Navigator Program

Christine Leopold¹ · Carina Araujo-Lane¹ · Carol Rosenberg³ · Melissa Gilkey² · Anita K. Wagner¹

Published online: 19 July 2019
© The Author(s) 2019

Information is lacking on whether treatment decision tools such as value frameworks that are based on ratings of safety, efficacy and price to help guide patient–oncologist decisions about highly-priced cancer treatments are useful in practice [1, 2]. We conducted a single-institution qualitative case study with two objectives: (1) to learn how a patient’s out-of-pocket (OOP) costs are considered in the care delivery process in a community oncology clinic; and (2) to explore oncologists’ perspectives on how useful two common value frameworks are in facilitating cost-informed treatment considerations. We selected an oncology practice, which is part of a multispecialty system of care for more than 700,000 patients in more than 30 locations, as this practice had specifically created the position of a patient financial navigator [3, 4] (hereafter referred to as navigator) to meet the growing need for financial support of cancer patients.

In July 2018, we conducted an hour-long interview with the navigator, and a 30-min focus group discussion with six oncologists. Both discussions were based on an interview guide that the research team had developed and pilot-tested (see the interview guide in the electronic supplementary material). We provided the National Comprehensive Cancer Network (NCCN) Evidence Block [5] and the American

Society of Clinical Oncology (ASCO) value framework [6] for treatments of chronic lymphocytic leukemia (CLL) and prostate cancer (PC) as examples for the discussion. These assessments rate treatments based on efficacy, safety, quality of evidence, and affordability (expressed as the average wholesale price). Two investigators (CAL and CL) used thematic content analysis to analyze transcribed interviews in Microsoft Excel (Microsoft Corporation, Redmond, WA, USA). The research protocol was approved by the Harvard Pilgrim Health Care Institutional Review Board.

1 Consideration of Costs in Practice

Oncologists reported that costs were almost exclusively considered in conversations between the navigator and the patient, but not during consultations with the oncologist due to the unpredictability and variability of OOP costs (Fig. 1). They described this process as a means to navigate uncertainty about insurance coverage and manage patients’ anxiety about financial burden, as described by participant # 5: “What I tell the patient is, ‘Okay, we want to do ibrutinib. We’ll see how much it costs for your copay. If the copay is too much for you, don’t panic. We have [a patient navigator] and if we can’t get the copay down, then we have other options.’ So I just tell them that we have avenues.” Participant # 2 stated: “Sometimes the copay is \$5 and you have no idea that it’s going to be that cheap, and some patients with the same disease and the same medication, their copay could be \$200. You know, some patients have deductibles that they have to meet before ... the medicines [they] have are covered, and some don’t. I mean, it’s just – some have commercial insurance, some have an HMO (health maintenance organization).”

All interviewed oncologists agreed that the navigator was tremendously valuable in the discussion about costs with patients, and was necessary in their community practice, as described by participant # 4: “(...) I think we’re also

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s41669-019-0170-z>) contains supplementary material, which is available to authorized users.

✉ Christine Leopold
christleopold@gmx.net

¹ Division of Health Policy and Insurance Research, Department of Population Medicine, Harvard Medical School and Harvard Pilgrim Health Care Institute, Landmark Center, 401 Park Drive Suite 401, Boston, MA 02215, USA

² Department of Health Behavior and Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC, USA

³ Department of Oncology and Hematology, Atrius Health, Boston, MA, USA

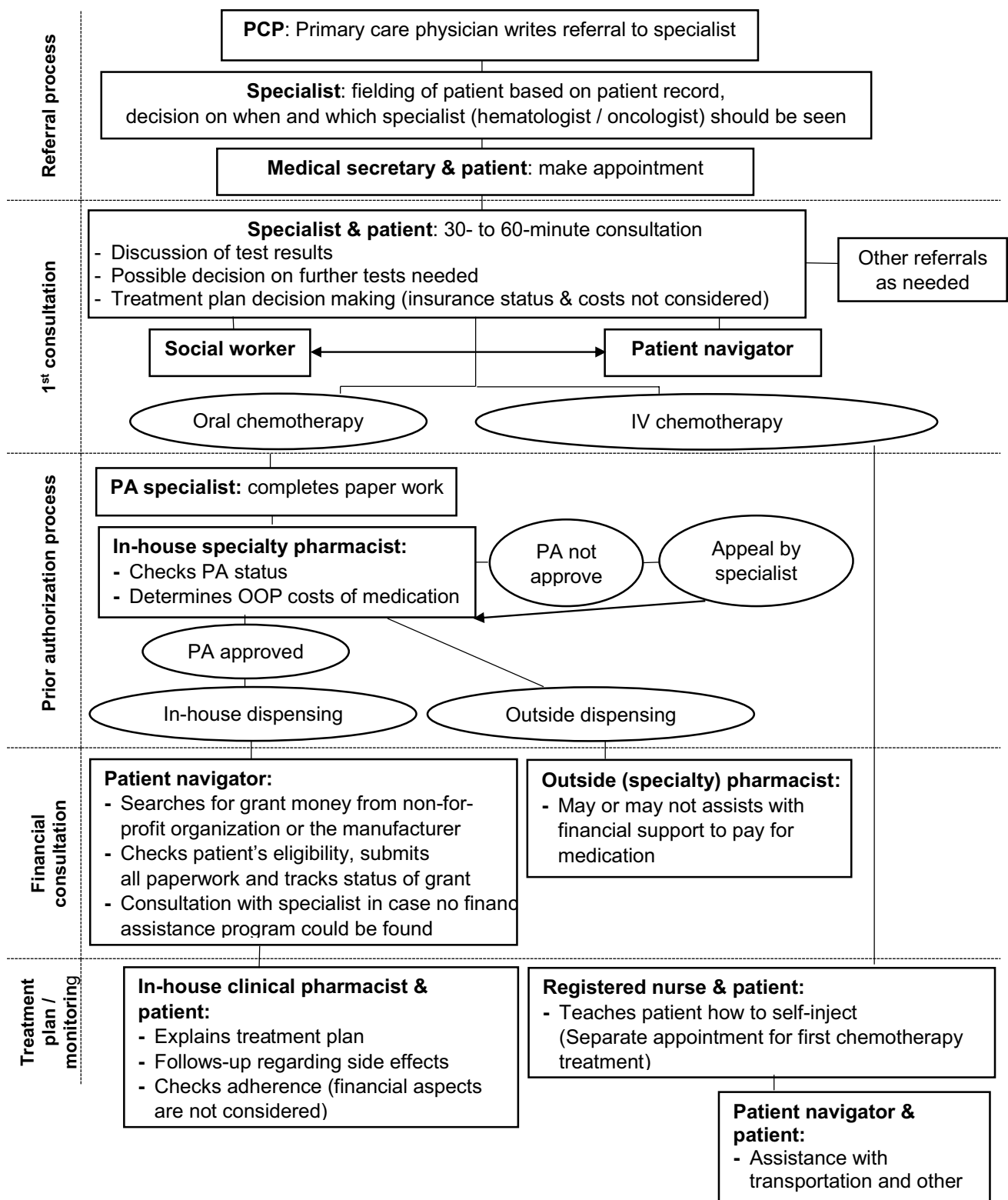


Fig. 1 Summary of interview and focus group discussion displaying the care delivery process in a community oncology/hematology department. *IV* intravenous, *OOP* out-of-pocket, *PA* prior authoriza-

tion, *PCP* primary care provider, *in-house dispensing* pharmacy service within the community clinic, *outside dispensing* any chain or independent pharmacy

privileged by having [...] our patient navigator, because ... I'm not sure in small practices they can do this, but we have. If the copay turns out to be high, then we have someone who can look into whether we can get ... help from the drug company or someplace ... that will offset this, which is, I think ... different in other places." Those cost discussions first took place after the oncologist and the patient had agreed on a treatment plan, the prior authorization process was finalized, and the patient's cost contribution known. The navigator's role was then to (1) identify options for patient financial support by researching and tracking patient assistance programs of non-profit organizations and manufacturers; (2) apply for and manage assistance programs for individual patients and the clinic; and (3) organize transportation, connect patients to support groups, and recommend health and wellness programs. Oncologists were only consulted if the navigator could not find a patient assistance program to decrease patients' copayments sufficiently. In those cases, oncologists tried to change therapies; for example, if an oral therapy cost was a barrier and comparable injectable therapy was available, providers would consider prescribing the injectable instead.

According to the navigator, costs were especially of concern for patients who are covered under Medicare Part D and have no prescription supplement and/or who need oral cancer treatments. Additionally, more and more patients with high-deductible health plans ask for assistance in understanding their health plan's coverage and their OOP costs.

2 The Role of Value Frameworks

While the navigator was not familiar with the concept of value frameworks, three of the six oncologists had heard about the NCCN framework, but not about the ASCO framework. None of the oncologists had used either framework. One oncologist saw the NCCN framework as potentially useful, but all expressed concerns about its practicality as information was difficult to capture quickly and definitions for the ratings were missing. They pointed out that none of the frameworks reflected actual costs of the therapy for the patient, or considered duration of therapy as described by participant # 4: "(...) some drugs like ibrutinib people stay on forever, and [for] some treatments it's a limited treatment, and they take six months of treatment and then they're [done]; they don't have anything ... for two years ... so the monoclonal antibodies ... alone would be that way. So ... your cost is going to be much greater in something that you take forever." The oncologists also pointed out the difficulty of differentiating between a health system perspective and a patient perspective when considering such value ratings as highlighted by participant # 1: "The struggle with some of these rankings, and they call it value frameworks,

[...], [is] trying to find the, [...] balance between the health system's perspective and the patient's and provider's perspectives". While the tools may address value (outcomes in relation to cost) on average, they do not address value or cost for the individual, which is important when making decisions with consideration of their clinical benefit and their financial impact on the patient. Overall, the oncologists emphasized the need for tools such as the NCCN and ASCO frameworks, but felt such tools would need to be easier to understand, be based on actual patient costs, and include useful benchmarks. For example, ratings of effectiveness and adverse effects of tamoxifen could be compared with those of aromatase inhibitors. For the tools to be used, oncologists would require training and assurance that development was free of biases that may influence ratings.

In summary, OOP expenses are of great concern for cancer patients. As documented by prior research, high OOP expenses can lead to delayed filling of prescriptions, skipping doses of medications risking negative clinical outcomes, and to bankruptcy of cancer patients [7–9]. Patients and physicians need to talk about OOP expenses [10, 11], however major barriers to those conversations exist, including lack of information on actual patient OOP costs given their insurance benefit type, and, for patients in high-deductible plans, where they are in meeting their annual deductible [12]. Like elsewhere [3, 13, 14], the navigator is key to conversations about OOP costs in the community oncology practice we studied. Existing value frameworks are not designed for use in the real-world patient–oncologist–navigator interactions. Even though oncologists showed general interest in using value frameworks to select treatments, they found the current presentation and information in the ASCO and NCCN frameworks insufficient. In addition, value comparisons of alternative treatments where they exist, e.g. injectable treatments [15] with lower OOP burden than oral anticancer medicines [16], are not considered in current value frameworks.

To facilitate discussion of OOP costs in cancer treatment selection, better tools are needed that inform decision making of patients, oncologists, and financial navigators. Such tools should provide comparative clinical and cost information, including patient OOP expenses given insurance coverage at the point of prescribing; they should come from trusted independent organizations and be accompanied by hands-on training in their use for providers and financial navigators.

Acknowledgements The authors thank the patient financial navigator and the oncologists and hematologists for participating in this study.

Data Availability Statement The interview transcripts are not publicly available due to them containing information that could compromise the privacy of research participants. Aggregated summaries are available upon request from the corresponding author (CL).

Compliance with Ethical Standards

Funding This study was funded by a departmental grant from the Harvard Pilgrim Health Care Institute.

Conflict of interest Christine Leopold has received a speaker honorarium from Sanofi Aventis. Carina Araujo-Lane, Carol Rosenberg, Melissa Gilkey, and Anita K. Wagner do not declare any conflicts of interests.

Informed consent Informed consent was obtained from all study participants.

Open Access This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits any noncommercial use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

References

- Shih Y-CT, Nasso SF, Zafar SY. Price transparency for whom? In search of out-of-pocket cost estimates to facilitate cost communication in cancer care. *Pharmacoeconomics*. 2018;36:259–61.
- Leopold C, Peppercorn JM, Zafar SY, Wagner AK. Defining value of cancer therapeutics: a health system perspective. *J Natl Cancer Inst*. 2018;110:699–703.
- Yezeffski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V. Impact of trained oncology financial navigators on patient out-of-pocket spending. *Am J Manag Care*. 2018;24(5 Suppl):S74–9.
- Yezeffski T, Schwemm A, Lentz M, Hone K, Shankaran V. Patient assistance programs: a valuable, yet imperfect, way to ease the financial toxicity of cancer care. *Semin Hematol*. 2018;55:185–8.
- National Comprehensive Cancer Network. NCCN Clinical practice guidelines in oncology (NCCN Guidelines®) with NCCN evidence Blocks™. NCCN Guidelines & Clinical Resources. 2016 [cited 6 Jan 2016]. <http://www.nccn.org/evidenceblocks/>.
- Schnipper LE, Davidson NE, Wollins DS, Blayney DW, Dicker AP, Ganz PA, et al. Updating the American Society of Clinical Oncology value framework: revisions and reflections in response to comments received. *J Clin Oncol*. 2016;34(24):2925–34.
- Chino F, Peppercorn JM, Rushing C, Kamal AH, Altomare I, Samsa G, et al. Out-of-pocket costs, financial distress, and underinsurance in cancer care. *JAMA Oncol*. 2017;3(11):1582–4.
- Lathan CS, Cronin A, Tucker-Seeley R, Zafar SY, Ayanian JZ, Schrag D. Association of financial strain with symptom burden and quality of life for patients with lung or colorectal cancer. *J Clin Oncol*. 2016;34:1732–40.
- Emanuel E. We can't afford the drugs that could cure cancer. *The Wall Street Journal*, 20 Sep 2018 [cited 18 Jan 2019]. <https://www.wsj.com/articles/we-cant-afford-the-drugs-that-could-cure-cancer-1537457740>.
- Kelly RJ, Forde PM, Elnahal SM, Forastiere AA, Rosner GL, Smith TJ. Patients and physicians can discuss costs of cancer treatment in the clinic. *J Oncol Pract*. 2015;11:308–12.
- Shih Y-CT, Chien C-R. A review of cost communication in oncology: patient attitude, provider acceptance, and outcome assessment: patient-physician cost communication. *Cancer*. 2017;123:928–39.
- Henrikson NB, Tuzzio L, Loggers ET, Miyoshi J, Buist DS. Patient and oncologist discussions about cancer care costs. *Support Care Cancer*. 2014;22:961–7.
- Mailloux C, Halesey E. Patient navigators as essential members of the healthcare team: a review of the literature. *J Nurs Patient Care*. 2018. <https://doi.org/10.4172/2573-4571.1000122>.
- Freeman HP. The origin, evolution, and principles of patient navigation. *Cancer Epidemiol Biomark Prev*. 2012;21:1614–7.
- Hunter WG, Zhang CZ, Hesson A, Davis JK, Kirby C, Williamson LD, 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. *Med Decis Mak*. 2016;36:900–10.
- Shih Y-CT, Xu Y, Liu L, Smieliauskas F. Rising prices of targeted oral anticancer medications and associated financial burden on medicare beneficiaries. *J Clin Oncol*. 2017;35:2482–9.