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Has the Current Oncology Value Paradigm Forgotten Patients' Time?

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### VIEWPOINT

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Author: Christopher M. Booth, MD, Division of Cancer Care and Epidemiology, Queen's University Cancer Research Institute, 10 Stuart St, Kingston, ON K7L 3N6, Canada (booth@queensu.ca). Has the Current Oncology Value Paradigm Forgotten Patients' Time? Too Little of a Good Thing

The past decade has seen the approval of some very effective treatments for cancer. However, despite notable advances, many new cancer drugs are associated with small benefits and high costs. While these concerns have stimulated important conversations about value, discussions are largely restricted to the magnitude of clinical benefit and drug prices. In this commentary, we discuss how the current value paradigm undervalues patients' time.

### Treatment Costs, Benefits, and the Existing Value Paradigm

Net treatment benefit considers improvements in outcomes together with side effects and quality of life (QOL). The American Society of Clinical Oncology Value Framework<sup>1</sup> and the European Society for Medical Oncology Magnitude of Clinical Benefit Scale<sup>2</sup> were designed to quantify the magnitude of benefit of new cancer medicines. These tools incorporate treatment intent, end points, and the extent to which outcomes are improved; side effects and QOL are also considered. We propose that existing value frameworks and clinical decision-making do not adequately account for the value of patient time, which is especially important near the end of life, when time is most scarce.

### The Value of Time

Initiating cancer treatment comes at the expense of patients' time and energy, which they cannot devote to other life pursuits or interests. When survival is long and treatment is effective, the relative cost of time spent on treatment may be minimal. However, when survival is short and treatment is less effective, the time devoted to receiving treatment can represent a substantial portion of a patient's remaining life. As oncologists, we routinely recommend sequential treatments after each progression. In conversations with patients, we carefully discuss potential benefits (ie, increased time, better QOL) together with the risk of adverse effects. However, less present in these discussions is an explicit acknowledgment of the amount of time and energy that a patient must invest in medical care to reap the potential benefits. The time invested in seeking cancer care is time that cannot be spent pursuing personal interests and other activities that matter to patients. It is not uncommon for patients to devote 1 full day every 2 to 3 weeks to cancer care owing to various time commitments (eg, travel time, physician appointment wait time, blood testing, imaging, and infusion time). During these medical care days, it is not possible for patients to work, play, travel, visit friends, or spend time with family.

While time has intrinsic value for all people, the concept of limited time becomes more acute in the context of an incurable illness. In the face of terminal bowel cancer, one patient referred to time lost for medical care as "appointmentitis." In this narrative account, the patient reminds us that "the diagnosis of cancer quickens time and patients lose patience. The good doctor will realize this."<sup>3</sup> High treatment burden is costly beyond the financial sense, with direct effects on patients' professional, social, and family life. This cost increases with later lines of therapy, which typically offer smaller gains and require increasing time in the cancer center. Before initiating therapy with palliative intent, oncologists and patients should carefully consider potential gains in survival against time spent at the clinic, which comes at the expense of patients spending time with family, traveling, or pursuing other interests. One of the few silver linings of the COVID-19 pandemic may be greater use of virtual care to minimize patient travel and appointment time.

It is unfortunate that cancer clinical trials do not measure patient time as an end point of interest. This becomes most relevant when 2 potential treatment options require different patient-level time investments. For example, an expensive treatment administered once per month could theoretically cost the same as a less expensive treatment administered twice per month. A costeffectiveness analysis would value both treatments the same way. But from a patient's perspective, the treatment requiring less time may be valued more highly. This view is best demonstrated by the fact that 90% of patients prefer oral chemotherapy to intravenous therapy, in large part because of increased convenience and ease of at-home administration.<sup>4</sup> A more complicated scenario arises when there is only 1 treatment option that has marginal (or uncertain) benefits and requires frequent patient medical visits.

To date, only a handful of studies have quantified patient time lost to treatments. Results of a 2008 survey of 238 patients with cancer suggested that the development of treatment-related toxicity led to an additional 4.5 hours of time a patient would need to devote to therapy.<sup>5</sup> Moreover, 77% of patients required their caregiver to attend these extra visits, highlighting the significant time cost to family members and caregivers.<sup>5</sup> Data extrapolated from a 1992 study of radiotherapy trials in lung cancer suggested that 5% to 25% of patients spent their entire survival time on active treatment.<sup>6</sup> This analysis comes from an older era when there were limited systemic therapy options for lung cancer. With the recent explosion of new treatment options in this context, one can only wonder what propor-

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tion of remaining survival time is devoted to cancer care. Contemporary data have not yet addressed this issue, but time spent on treatment is almost certainly much higher than in the past. As the survival benefit of a treatment diminishes and the frequency of visits increases, the proportion of added survival time lost to therapy visits also increases. In a 2020 study, Bange et al<sup>7</sup> showed that patients receiving palliative chemotherapy for pancreatic cancer spent 10% of their living days actively seeking medical care; this did not include time for laboratory testing or hospital admissions. With expected survival of less than 1 year and palliative chemotherapy adding approximately 1 to 2 months of median survival in routine practice, this pivotal study illustrates that a substantial proportion (and perhaps all) of the survival gain from treatment may be offset by time spent at the cancer center. Given that time (and the potential loss of personal, professional, and social opportunities it represents) is an indisputably important metric to patients, research efforts are needed to quantify the time commitment of cancer care. Moreover, our field would benefit from studies that explore how time

committed to care changes from first-line to second- and third-line treatments. These data would be particularly useful for patients with advanced disease who are navigating end-of-life treatment decisions, which may involve forgoing valuable time at home in favor of pursing therapy that is unlikely to alter their clinical course.

At its core, the art of oncology involves guiding patients through complex treatment decisions to ensure that the care they receive aligns with their values and preferences. Although oncologists routinely discuss how treatments may (or may not) help patients live longer and how side effects may affect QOL, we have not done a good job of helping patients understand the time required for cancer care and the inevitable trade-offs. Clinicians can do a better job of acknowledging this issue in care delivery, and the research community needs to generate data to guide these important discussions. Finally, although current value frameworks and economic models have allowed us to better quantify the net benefit associated with cancer therapy, holistic cancer care must consider patient time, which, for many, is the most important variable of all.

### ARTICLE INFORMATION

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