In Reply

We thank Drs. Strohbehn and Daugherty [1] for their interest in our recently published paper, “Exploring patient decision making regarding discontinuation of TKIs for CML” [2]. We conducted 22 semistructured interviews with patients with chronic myeloid leukemia (CML) regarding their views on discontinuation of tyrosine kinase inhibitor (TKI) therapy [2]. As stated in our title and throughout the article, this was an exploratory study, a first step toward understanding and supporting clinical decision making in CML, but nevertheless—to our knowledge—the first published qualitative approach that brings patients’ voices to the table. More to the point that Strohbehn and Daugherty made about including patient voices in research design, we agree. We have an active patient advisory panel of patients with CML that participates in our research, including this interview study, our clinical trial of TKI discontinuation [3], and other studies [4].

Regarding the incorporation of prospect theory, we do not believe that it (or any of several other competing frameworks for decision making under uncertainty) [5] is incompatible with our work. We agree wholeheartedly that “a good medical decision reflects the patient’s values, applies scientific evidence, considers medical expertise, and acknowledges uncertainty,” as stated in the Verma et al. viewpoint that Strohbehn and Daugherty cited [6], and we thank them for making this link explicit. To clarify the concepts of “risk” and “ambiguity,” the language we used in the questions to patients was about what they thought their “chance” was of remaining in a treatment-free remission and what they thought the average patient’s chances were. Chance can be considered a lay-language representation of total subjective uncertainty that integrates probability of events and uncertainty about those probabilities. Although we agree that risk and ambiguity are distinct concepts necessary to resolve preference reversals observed in carefully constructed choice experiments [7], we do not agree that it is necessary to disentangle them in our qualitative study. From the point of view of individual patients with CML, it is likely of relatively little distinction whether a relapse occurs because of an “unlucky” draw (risk) or because the probability of relapse was underestimated (ambiguity) [8]. By asking patients about their perceptions of both their own and the average patient’s chances of relapse and showing the differences between the two, we have demonstrated evidence that is consistent with “humans’ underlying tendencies to massage probabilities” [1].

Our intent was never to “surprise” readers. By outlining the variety of factors that patients told us they thought about when making this decision, we neither assumed nor suggested that patients do create or should create formal “pros” and “cons” lists as part of a rational or heuristic decision-making process. As we stated, we see inclusion of the patient perspective on this decision as foundational to thinking about how to better support the patients and

physicians who will be making this decision. Future work should try to further unpack this decision and to capture the behavioral biases that drive treatment decision making in this context.

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Disclosures

Charles A. Schiffer: Astellas, Ambit, Pfizer, Takeda, Pharmacyclics, Juno, Celgene, Puma, Genentech (C/A), Celgene, Novartis, Bristol-Myers Squibb, Ariad, Micromedex, Pharmacyclics (RF); **Ehab Atallah:** Bristol-Myers Squibb, Novartis, Takeda, Pfizer (C/A), Novartis, Bristol-Myers Squibb, Pfizer (RF). The other authors indicated no financial relationships.

(C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honoraria received; (OI) Ownership interests; (IP) Intellectual property rights/inventor/patent holder; (SAB) Scientific advisory board

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