EDITORIAL

What if?: Regret and cancer-related decisions

Deb Feldman-Stewart, PhD;* D. Robert Siemens, MD, FRCSC*[†]

*Cancer Care and Epidemiology, Cancer Research Institute at Queen's University, Kingston, ON; †Department of Urology, Queen's University, Kingston, ON; and CUAJ Editor-in-chief

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n today's age of instant, virtually global medical information exchange from seemingly endless sources, use of attention-grabbing headlines/titles is as common as those (disturbingly effective) ones found on check-out line magazines. We hope readers of CUAJ find emailed electronic table of contents and links to our new digital edition of the journal helpful to review content at convenient times and in different formats. However, it's likely that your inboxes are full of similar offerings from other medical journals, associations and online services all vying for your attention and desirous of a substantial click-through rate.

Here's a recent subject line from the CMA that recently grabbed our attention: "Approximately 12% of men regret prostate cancer treatment decisions." The email originated from POEM (or Patient Oriented Evidence that Matters), a generally fascinating daily update of recent studies on patient-forward research. The newsletter goes on to a précis of a recent article from Morris and colleagues in *Cancer*, concluding that (we paraphrase) as most prostate cancers do not kill men, and treatment leads to a decrease in quality of life, guiding men to watchful waiting would be a wise strategy.¹ A second cup of coffee could wait. It was time to rev up Google Scholar in search of this article.

Cancer-related decisions, particularly for men with a diagnosis of localized prostate cancer, are challenging and demand a complex understanding and evaluation of both medical and psycho-social repercussions all within the context of personal values and beliefs. Decisional regret or remorse is an obviously deleterious outcome after any medical decision – one that is likely under-examined in comprehensive patient/spousal counselling or follow-up after cancer management. Regret is the negative emotion experienced when we suspect that an alternative course of action would have resulted in a better outcome. It is also an ecologically valid quality indicator, as people often naturally include "anticipated regret," considering the potential for decisional regret as part of comparing options when making a decision. Although well-studied in other fields, until recently these concepts have seldom attracted the attention they deserve in the medical literature.

The study of decisional regret in localized prostate cancer management would seem imperative given its incidence and the substantial vagaries in our understanding of comparative efficacy of its management. Regret is unhealthy and associated with, and perhaps exacerbating, side effects of treatment leading to stressful attempts at unraveling original decisions. Several studies, many from Canadian investigators, have described (albeit often low) decisional regret after prostate cancer management. This negative experience has been associated with declines in sexual or urinary functioning experienced by our patients. Regret also varies with time and is likely associated with suboptimally delivered patient information. However, examining decisional regret is not that simple, both in its measurement or understanding its implications for patient care.

Several assessment instruments have been developed that attempt to quantify regret, but psychological research has emphasized the complexity of the concept. The tool utilized in the manuscript by Morris and colleagues included 2 questions: (1) would the patient have been better off with a different treatment, and (2) how much time could the patient have spent wishing he could change his mind. However, the responses in this study are simply dichotomized (yes/no) and reported at a single time-point with variable lengths of follow-up after management. As well, the investigators report on a highly variable cohort, including men with low risk cancer, as well as those with advanced, metastatic disease. Using a simplistic assessment of men with such different decisions and subsequent treatments and reporting them in a summary fashion is bound to lead to spurious findings.

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Nonetheless, given its relevance to shared-decision making, further work understanding and potentially mitigating decisional regret for our patients deserves some priority. Existing tools require further development with a specific eye on clarifying the purpose for using regret assessment instruments. Minimizing regret may positively contribute to post-treatment adjustments, satisfaction and quality of life - no easy task. Decision regret comes from at least three sources: (1) from the decision process, (2) from the choice actually made, and (3) from the experienced consequences of the choice. Interestingly, Morris and colleagues found the highest increase in regret was in patients who were "very unsatisfied with [their] understanding of potential treatment side effects." However, the authors also noted that actual understanding did not modify that regret - just providing information is not enough to reduce regret. Help with their decision-making (otherwise called decision support) helps patients beyond just providing information. Widespread availability and use of clinical decision aids, one type of decision support, may represent one practical approach. Facilitating patient-driven decision-making by providing relevant information at the same time as clarifying and incorporating patient values and preferences may help to reduce decisional conflict and subsequent regret. Canada has taken one step in that direction: Prostate Cancer Canada is developing a patient portal (one-stop shopping for all prostate cancer patients), which includes a Canadian decision aid that demonstrated reduced decisional regret compared to information alone in a randomized controlled trial.

The terms "regret" and "prostate cancer" in the title of any article will undoubtedly garnish general interest: a significant but complex concept that deserves further study. Better understanding of regret and how it is generated is the best way to help reduce it for prostate cancer patients.

Reference

 Morris BB, Farnan L, Song L, et al. Treatment decisional regret among men with prostate cancer: Racial differences and influential factors in the North Carolina Health Access and Prostate Cancer Treatment Project (HCaP-NC). *Cancer* 2015;121:2029-35. http://dx.doi.org/10.1002/cncr.29309. Epub 2015 Mar 3.