EDITORIAL

What's in your toolkit? Guiding our patients through their shared decision-making

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In this edition of the *Canadian Urological Association Journal,* there exists an underlying theme regarding the informational needs of patients, including those requiring a metabolic workup for stones and those facing different treatment preferences for localized prostate cancer. Although it seems self-evident, our patients need and deserve timely, accurate information to make decisions around their diagnostic and treatment options. Failure to provide sufficient information is the most frequent source of patient dissatisfaction and decision regret. Yet the art and science of developing and providing health information that can be optimally used is far from perfect. Despite the amount of available resources and time we spend counselling our patients with prostate cancer, the article by Feldman-Steward et al suggests that almost one-quarter of all prostate cancer patients surveyed wanted more help than they received in making a treatment decision.[1] Of those who desired more help, roughly half reported not feeling well-informed.

One might suppose that the optics of this implication depend on whether you see the glass "half-full" or "half-empty." The fact that 52% of those who wanted more help making a decision still felt well-informed suggests that additional information may not aid in the decision-making process for these specific individuals. That in and of itself may suggest to some that all the counselling in the world may not be sufficient, and these patients are simply waiting for a divine epiphany to help guide their decision-making process. However, to others this may suggest half these patients do require more information and half these patients require *different* information.

Prostate cancer care is complex and patients may have difficulty interpreting risks and benefits. These are frequently single-event probabilities of binary outcomes, provided to patients in the form of estimated risk ratios. Fundamentally, understanding this concept may be an issue with patient numeracy and health literacy, rather than in deficits in the *quantity* of information provided. Nonetheless, if we measure the *quality* of our treatment discussion by a patient's ability to understand the encounter, then we provide patients the same quality of care by discussing with them risk ratios they may not understand as we do by sitting silently across from them and ignoring their questions. Thus, it is not surprising that limited health literacy is associated with a preference for physician-directed as opposed to patient-directed treatment decisions.[2]

In an era where we are striving toward increased patient-centred care, it behooves us to ensure that patients understand the information we are attempting to convey. There is evidence that decision aids improve patient knowledge, reduce decisional regret, improve patient understanding of risk perception, and lead to patients taking on a more active role in their treatment decisions.[3] If we cannot provide patients the information they require in a format they understand, or at least the resources to acquire that information, then patients may be forced to look to "Dr. Google" and less reputable sources.

In this same issue of the *CUAJ*, Kobes et al documented the questionable reliability of many of the prostate cancer websites that patients may look to for their informational needs.[4] Only 27% of the online websites surveyed identified the author of the information on the site. Furthermore, 60% of websites did not contain a list of references and only 25% contained two or more reliable references. These data indicate that patients are placed in the middle of a difficult conundrum, where they may not understand the information their urologist provides them, but the information they seek out to clarify these discussions may be of questionable quality.

High-quality decisions aids have been suggested as a solution to help remedy this challenge. However, before we declare that all patients must be provided disease-specific decision aids individualized to a numeracy and literacy level congruent with that particular patient, it may surprise some to learn then that decision aids themselves may be subject to the same flaws as the websites surveyed by Kobes et al. In an article published earlier this year, Dannenberg et al found that many organizations do not use a standardized process to summarize the evidence contained within decision aids.[5]

As the evolving paradigm of patient-centred care moves forward, we must continue to search for solutions to convey complex health information to patients in a format that allows them to understand and advocate for themselves.

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CUOS Canadian Uro-Oncology Summit 2019

On behalf of the Canadian Uro-Oncology Group (CUOG), I am pleased to announce the first annual premiere meeting for uro-oncology specialists entitled, Canadian Uro-Oncology Summit (CUOS). In consultation with GUMOC, GUROC and CNUP, we have decided to all come together and establish a meeting where Canadian experts can exchange ideas, new research findings and clinical expertise.

This meeting will include poster, podia and plenary sessions. Separate breakout sessions for specialty-specific concerns also will be featured. All abstracts will be published in the Canadian Urological Association Journal (CUAJ).

Included in the registration fee, all food and beverage will be served in a state-of-the-art exhibition hall. A networking and social event will also be planned.

The CUA Office of Education will oversee the coordination of the event, as well as the accreditation process for all specialty groups.

We look forward to your participation in this inaugural event.

Neil Fleshner, CUOG Chair

January 10-12, 2019
Westin Harbour Castle
Toronto, ON

Early Bird Registration ends November 1, 2018

Accommodations
Westin Harbour Castle Hotel Toronto
Preferred rate available until December 17, 2018.
Group name is CUA-CUOS Jan2019

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