Men's knowledge on prostate cancer needs improving
16 April 2019, by Patty Wellborn

UBC researchers have determined the majority of men struggle when it comes to understanding the diagnosis and treatment of prostate cancer.

Professors Joan Bottorff and John Oliffe are scientists with UBC's Men's Health Research Program. Together, while studying men's knowledge or literacy of prostate cancer, they realized many are in the dark when it comes to what they know about the disease. And, more importantly, what direction to take after diagnosis.

"In terms of health literacy, there is a long history of people saying men are not up to speed," says Oliffe. "This includes their knowledge when it comes to understanding prescription drugs and dosages, whether they know the stages of a disease and how they apply the knowledge they have."

Health literacy is the ability to access, understand and use health-related information to make informed decisions and manage personal health. However, when it comes to prostate cancer, the information is overwhelming for many men, adds research coordinator and study lead author Cherisse Seaton.

"Our research looks at how men apply the knowledge they have," she says. "Quite often there is so much information out there and it's complex in terms of choice."

Prostate cancer is the most common cancer among Canadian men and it has a high survival rate. However, says Seaton, low health literacy is considered a risk factor for poor health and poor decision-making.

"Men have some big decisions to make after diagnosis," says Seaton. "Not all prostate cancers are aggressive and it can be challenging to predict if a patient has slow-growing cancer or one that is aggressive. The patients have to decide what type of treatment course to follow. To do that they need to be well informed and understand of all the options."

A common treatment option—active surveillance—calls for no surgery or active treatments. The goal is to wait out the disease while consulting regularly with a doctor. While active surveillance can be an option, the study shows more than 91 per cent of men surveyed opted for treatment.

"There are some men who just really want to get rid of the cancer regardless of what they are told," says Bottorff, who teaches in UBC Okanagan School of Nursing. "They go forward with the surgery or a more aggressive treatment than they might need, quite often from fear or lack of knowledge. These active treatment options have considerable side effects and we believe the better the men's health literacy, the better they will do when it comes to making informed choices and avoiding decisional regret."

Although research shows men rate their understanding of health information highly, many feel they do not have enough information to manage their personal health.

To help with men's health literacy for prostate cancer, the Men's Health Research team created an interactive website titled If I Were Tom. The site, Oliffe explains, is useful for men right after diagnosis. A number of videos follow fictional patient named Tom through the prostate test, diagnosis and a treatment decision. Site visitors can make decisions with Tom, and learn of the many options available. The interactive website also shares messages from survivors, health care providers and family members.

"Our research showed that even though men had a lot of interaction with health care providers, and there are tools out there, they still felt they needed more information," says Bottorff. "Clearly, we need
to find other ways to connect men with the information they are looking for. This website is an effort to address those information needs in a way that is accessible to men."

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