



Health literacy and consumerism

The language used in prostate cancer can be quite complex, and patients can be confused by the huge amount of information that is available to them. Many men also have to decide what treatment they will have and begin to ‘shop around’ for treatments and doctors. At PCSGs men learn the language of prostate cancer and how to use that language to understand their prostate cancer and ask questions about treatments.

Prostate cancer numbers

The prostate specific antigen (PSA) and the Gleason score were two important pieces of information for men to understand and the PCSGs encouraged men to find out these details before making any treatment decision. A 74-year-old group leader explained that newly diagnosed men who attended the PCSG were told to get that information as a starting point so that group members could help them understand *their* prostate cancer numbers:

All we’re here to do is say, hey, you got it. Do you have the answers to the following questions, like what was your PSA? What was your Gleason score? What was your, how long is it da, da, da, da? And from that we can make some suggestions based on our own experiences. But the main thing is in most cases we try and get a handle on the Gleason score as early as we can. And if they haven’t got it because they didn’t know to ask, we send them for it. Go and find out.

Shopping around

Men at PCSGs also talked about treatment options. At one group meeting, a man talked about choosing to have HiFu, a treatment that was only available in a neighboring province. Men also talked about surgery options including grafting nerves from the ankle to increase the chances of being able to get an erection after the treatment. Hearing about these options at PCSGs helped men to ask their doctor about all the possible treatments, as an 87-year-old man explained:

Well I do know that from the exchange of experiences and knowledge some men have been able to go back to their doctors and ask and more or less demand better treatment. I know those things have happened. They have found out that there are things that they can do which they never found out [about] until they heard the stories here.