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January 7, 2019

https://doi.org/10.1016/j.eururo.2019.01.010

Patterns of Knowledge Acquisition Among Men Undergoing Radical Prostatectomy

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We previously conducted an extensive questionnaire-based study of patient-based outcomes among men after radical prostatectomy (RP) at Herlev and Gentofte Hospital, Denmark [1]. Among other issues, the questionnaire contained questions regarding patients' knowledge acquisition about prostate cancer before their surgery. Therefore, we read with great interest the paper by Loeb and co-workers [2] detailing the problems with prostate cancer information provided on YouTube. To the best of our knowledge, no systematic information on the proportion of prostate cancer patients who seek such information has been published, and therefore we find it appropriate to share our findings.

Questionnaires were mailed between December 2012 and February 2013 to men who had previously undergone RP [1]. A total of 386 patients were invited to participate and 316 usable questionnaires (82%) were returned. Patient demographics are presented in Table 1. Of these men, 284 (89.9%) had sought information about their cancer from sources other than their urologist. Most had used more than one source: 181 (57.3%) had consulted their family practitioner, 222 (70.3%) had sought advice from the official prostate cancer patient association, 165 (52.2%) had discussed the issue with perceived knowledgeable friends or family members, and 254 (80.4%) obtained extra information from the mainstream media. Importantly, 227 (71.8%) had looked for information online. Of this final group, 32 (14.1%) had sought information from officially recognized health care sites only, whereas 195 (85.9%) had also conducted more general searches leading them to other types of websites including YouTube. Fifty-two men (22.9%) had only visited such unofficial sites. The results are summarized in Table 2. On multivariate logistic regression analysis that included the parameters in Table 1, a higher preoperative International Index of Erectile Function-5 score (odds ratio [OR] 1.040, 95% confidence interval [CI] 1.009–10.73; $p = 0.012$) and current employment (OR 2.86, 95% CI 1.64–4.98; $p = 0.0002$) were independent predictors for seeking online information outside officially recognized sites. The main limitation of our data is that we queried patients who had chosen to undergo RP. Therefore, there might be a selection bias towards men with a relatively high degree of trust in the established medical community. The proportion of men who seek knowledge about prostate cancer on unreliable websites might be even higher than estimated here.

As shown by Loeb and co-workers [2], information about prostate cancer displayed on YouTube may be inaccurate or

Table 1 – Patient demographics ($n = 316$)

Parameter	Result
Median age at the time of the operation, yr (range)	64 (43–76)
Median time since surgery, mo (range)	17 (3–36)
Median body mass index, kg/m^2 (range)	25.5 (14.8–37.4)
In a relationship, *n* (%)	289 (91)
Currently employed, *n* (%)	128 (41)
Smoker, *n* (%)	32 (10)
Mean preoperative IIEF-5 score (95% CI)	21.5 (20.6–22.5)
Mean preoperative DAN-PSS (95% CI)	6.3 (5.2–7.5)
One or more comorbidities, *n* (%)	145 (46)
D'Amico high risk, *n* (%)	86 (27)
D'Amico intermediate risk, *n* (%)	198 (63)
D'Amico low risk, *n* (%)	32 (10)

IIEF-5 = International Index of Erectile Function-5; DAN-PSS = Danish Prostate Symptom Score; CI = confidence interval.

Table 2 – Sources of knowledge for men undergoing radical prostatectomy ($n = 316$)

Knowledge acquisition	Men, *n* (%)
Sought information from sources other than their urologist	284 (89.9)
Family practitioner	181 (57.3)
Official prostate cancer patient association	222 (70.3)
Friends and family members	165 (52.2)
Mainstream media	254 (80.4)
Online information	227 (71.8)
Both official and unofficial websites	143 (63.0)
Official websites only	32 (14.1)
Unofficial websites only	52 (22.9)

directly misleading. There is no reason to believe that other unofficial online sources deliver more reliable information. In fact, even health care provider websites may contain information of low quality [3]. Thus, patients who seek knowledge online may be misled. The problem is exacerbated by patients sometimes having difficulty understanding the information they find [4]. While some previous studies have provided knowledge about the number of people who view prostate cancer–related content online, they do not tell us to what extent our actual patients view such material. Our results provide a sense of the proportion and can help in identifying the patients who clinicians should be especially aware of. They also highlight the need for patient-oriented information initiatives such as the European Association of Urology patient information program.

Conflicts of interest: Mikkel Fode is an advisory board member for Astellas Pharma A/S and has received speaker honoraria from Astellas Pharma A/S and Ferring Pharmaceuticals. Peter B. Østergren has received speaker honoraria from Astellas Pharma A/S, Ferring Pharmaceuticals, and IPSEN, consultancy honoraria from Astellas Pharma A/S, and advisory board honoraria from IPSEN. Anders Frey and Jens Sønksen have nothing to disclose.

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January 9, 2019

https://doi.org/10.1016/j.eururo.2019.01.018