Press release: Europa Uomo & European Association of Urology congress

*Largest-ever study by patients shows prostate cancer treatment has significant impact on quality of life*

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*Type of Study: not peer-reviewed/patient survey/human subjects*

- Biggest-ever survey of how prostate cancer patients feel after treatment
- Half who replied report loss of sexual function is a significant problem
- Different treatments impact quality of life differently
- Early detection and treatment gives better quality of life

Findings from the first international prostate cancer quality of life study conducted by patients themselves reports that significant numbers of men treated for the disease are struggling with continence and sexual problems after treatment. Results suggest that any treatment apart from active surveillance may negatively affect quality of life, and indicate that for many men these effects may be greater than previously thought.

The findings of the Europa Uomo Patient Reported Outcomes Study (EUPROMS) were announced today by Europa Uomo Chairman André Deschamps at the European Association of Urology’s Virtual Congress. He reported that “The analysis of survey responses showed that urinary incontinence and sexual function were the two areas where men reported the lowest quality of life scores – much lower compared to the averages reported in clinical studies.”

EUPROMS gathered data from 2,943 European men from 25 countries. The respondents had an average age of 70 (all were over 45), and on average had been diagnosed with prostate cancer at the age of 64, meaning that they were reporting on quality of life 6 years after treatment.

Overall, 50% of men who replied to the questionnaire and had been treated for prostate cancer said that loss of sexual function (including the ability to have an erection or reach orgasm) was a big (28%) or moderate (22%) problem for them.

“We often hear that decline in sexual functioning is a relatively small problem for prostate cancer patients and the effect on their quality of life should not be exaggerated,” said André
Deschamps. “We also hear that prostate cancer is typically a disease of ‘old men’, implying that the loss of sexual function is less relevant. This survey paints a different picture.”

Respondents also report that different treatments have different effects on quality of life; radical prostatectomy (surgical removal of the prostate) has the largest reported impact on urinary incontinence. Radiotherapy was shown to double the fatigue a patient experiences in comparison to surgery, whereas chemotherapy triples the fatigue score. The impact of radiotherapy on sexual function is worse than radical prostatectomy but both have a severe impact.

Results indicate that the best quality of life scores are seen where the cancer is discovered in an early, curable stage. “This means efforts toward early detection and awareness are essential to avoid unnecessary deterioration in quality of life. Wherever it is possible and safe, active surveillance should be considered the first line treatment to ensure best quality of life.” said André Deschamps.

He continued “Our findings provide patients and health care professionals with a snapshot of the impact of treatments. We hope they will be used to set realistic expectations of the effects of the different treatments for prostate cancer on quality of life. They show that the effects of prostate cancer often don’t stop after treatment, and even those who are treated successfully for their cancer may have significant problems.”

He added “The results of this survey are different from clinical studies using the same validated questionnaires. This doesn’t replace previous studies, but it does, suggest further investigation is needed. This is a huge survey, which is the great strength of the work, so I’d like to say thank you to all patients and volunteers who spent hours making this survey a success.”

Commenting, Professor Arnulf Stenzl (Tübingen University, Germany), the European Association of Urology’s Adjunct Secretary General – Executive Member Science, said:

“This is a valuable survey, the largest of its kind ever undertaken. It uses the same questionnaires used in standard clinical settings, but it is both qualitatively and quantitatively different to the kind of study usually undertaken, so it needs to be read alongside these previous studies. It has several strong points, not least that this is multi-
national, and so will reflect the impact of treatment on a wide range of patients, with different health systems. We completely agree that early detection and treatment is essential if we are to avoid problems with quality of life later on. It shows that for many men, quality of life can be poor after most prostate cancer treatment, especially in advanced disease. This message is clear, and we need to listen to the voices of these patients.”

Survey details

The EUPROMS survey was available in nineteen languages, via a link advertised by Europa Uomo’s member organisations, its website (www.europa-uomo.org), newsletter and social media. Europa Uomo also used its network of supportive urologists to promote the survey and encourage patients to complete it. Respondents were asked to complete a 20-minute online survey, using the following 3 standard validated quality of life questionnaires, EPIC-26, EORTC-QLQ-C30, and EQ-5D-5L

Analysis of the data was conducted by Professor Monique Roobol of the Erasmus University Medical Centre, Department of Urology, Rotterdam, who said:

“This study is important because it was initiated by patients and meant for patients. The questionnaires were completed unrelated to a hospital visit, which means respondents had more freedom to answer and provides insight into the effect of treatment on quality of life over a longer period.”

Background information

Europa Uomo is a European advocacy movement for men representing and supporting 27 prostate patients’ groups across Europe. It works to improve diagnosis, treatment and support by influencing policy at national and international level. It works with health professionals throughout Europe to help them understand patient perspectives. It also supports its member organisations as they strive to improve services and awareness in their own countries. www.europa-uomo.org

Twitter: @europa_uomo

The 35th European Association of Urology conference takes place online from 17-19 July, 2020. This replaces the physical conference which was scheduled to take place in Amsterdam. The EAU conference is the largest and most important urology congress in Europe, with up to 14,000 attendees. Conference website https://eaucongress.uroweb.org/

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