



Prostate cancer patient led study shows significant impact on quality of life after treatment.

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A world-first international prostate cancer quality of life study has been carried out by prostate cancer patients themselves. This is the largest study ever conducted by patients and its findings suggest that the different types of treatment for prostate cancer have differing impacts on quality of life. The study suggests that significant numbers of men struggle with urinary incontinence and sexual problems after treatment and that the impact on their quality of life may be greater than previously thought.

[Europa Uomo](#) is a patient-led non-governmental association that was launched in Milan, Italy in 2004 and is currently based in Antwerp, Belgium. It is a coalition of prostate cancer patient groups with representation in 18 European countries. The organisation focuses on prostate cancer awareness, early detection, optimal treatment, multi-professional care, quality of life and patient advocacy.

Earlier this week Europa Uomo's chairman, André Deschamps, presented the findings of the Europa Uomo Patient Reported Outcomes Study ([EUPROMS](#)) at the 2020 European Association of Urology Virtual Congress.

EUPROMS is the largest-ever patient-driven quality of life study to be conducted in Europe. The study was conducted by a 20-minute survey translated into 19 different languages and widely promoted by Europa Uomo's member organisations and by urologists. The survey was comprised of 3 validated questionnaires which are often used by researchers to assess general health status (EQ-5D), quality of life after cancer treatment (EORTC-QLQ-C30) and the effects of urinary, bowel, sexual, and hormonal symptoms on a man's quality of life after prostate cancer treatment (EPIC-26).



The data from the survey was analysed by Professor Monique Roobol at Erasmus University Medical Centre, Department of Urology, Rotterdam, Holland 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.”*

A total of 2943 men responded to the survey from 24 different European countries. The average age of the men who responded was 70 and all were over the age of 45. The average age of diagnosis was 64, so many of the men had been living with the effects of prostate cancer treatment for 6 or more years.

The respondents had received various forms of treatment for prostate cancer with 57% receiving a single type of treatment, 22% receiving two different treatments, 19% receiving 3 different treatments and 2% receiving 4 or more different treatments.

The results from the EORTC-QLQ-C30 questionnaire identified fatigue (mean score 24) and insomnia (mean score 22) as the commonest symptoms. The mean score is a figure out of 100, lower scores mean a symptom is less common. Men who had a radical prostatectomy (removal of the prostate) were less likely to experience fatigue (mean score 11), then men who had radiation therapy (mean score 22) or chemotherapy (mean score 33) to treat their prostate cancer. Insomnia was less related to the type of treatment and more related to the stage of the disease. Insomnia was more common in men on chemotherapy (a treatment for advanced high-risk prostate cancer) and was rare in men on Active Surveillance (a treatment for low risk cancer).

Results from the EPIC-26 questionnaire ranked urinary incontinence and sexual function problems (including the ability to have an erection or reach orgasm) as the most prevalent symptoms. For this questionnaire, the higher the score, the less worrisome the symptom is. Urinary incontinence was not a problem for men on Active Surveillance with a mean score of 100. The largest impact on urinary incontinence was seen with men who had a radical prostatectomy. These men had mean scores of 65 to 73 depending on what other treatments they had also received while men on radiation therapy fared better with urinary incontinence scores of 73 to 100.

A different picture was seen with sexual function scores from the EPIC-26 questionnaire. Men on Active Surveillance reported a mean sexual function score of 57. Radiation treatment had a greater impact on sexual function with scores of 15 to 18 seen in this group compared with 15 to 26 in men



who had had a radical prostatectomy. The worst impact on sexual function (score mean of 12) was seen with men on chemotherapy. Of all the men who completed the survey, 50% reported loss of sexual function that was either a big problem (28%) or a moderate problem (22%) for them.

In a press release André Deschamps said, *“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.”* He went on to say, *“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.”*

The best quality of life scores were observed when prostate cancer was detected earlier at a stage where it was curable. In addition, Active Surveillance had the least impact on quality of life. Deschamps said *“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.”*

This study provides some very interesting insights that warrant further investigation. The strength of the study lies in the large number of patients involved, the long-term nature of the study (6 years post diagnosis for many men) and the use of validated questionnaires. In addition, the multi-national nature of the study brings together the experiences of a range of different patients being treated in very different health systems.

In the words of Professor Arnulf Stenzl (Tübingen University, Germany), the European Association of Urology’s Adjunct Secretary General – Executive Member Science, *“This is a valuable survey, the largest of its kind ever undertaken. It shows that for many men, quality of life can be poor after most prostate cancer treatments, especially in advanced disease. This message is clear, and we need to listen to the voices of these patients.”*

To more fully understand the effects that different treatments for prostate cancer have on quality of life, further large scale multi-national clinical studies are necessary. Being clearly informed about the possible short- and long-term symptoms from prostate cancer treatment will help men make the best treatment decisions for them and better manage any symptoms they may experience because of their chosen treatment.

PCFA is dedicated to improving survivorship outcomes locally and globally. Stay posted for more news on our work in this area.