

European Association of Urology – Press release

[Wives of many prostate cancer sufferers made ill or feel undermined by the disease](#)

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Copenhagen: Many wives of advanced prostate cancer sufferers feel that their lives are being undermined by their husband's illness, with nearly half reporting that their own health suffered. In addition a focus subgroup has revealed that many feel isolated and fearful, and worry about the role change in their lives as their husband's cancer advances. This study, developed with the wives of men with metastatic prostate cancer who were being treated with hormone therapy, is amongst the first carried out on how prostate cancer affects the partners of sufferers. It was presented yesterday at the EAU conference in Copenhagen.

Prostate cancer is the most common male cancer. Prostate cancer which metastasises to other parts of the body is often difficult or impossible to cure, and so is often treated with androgen deprivation therapy (ADT), which slows down the tumour growth. ADT shuts down production of the hormone testosterone, but that leads to fatigue, frailty, and loss of sexual drive. The effects of prostate cancer and its treatment have been extensively studied in men, but there is almost no work on how this affects their partners.

A team of Danish researchers from Herlev and Gentofte University Hospital, led by registered nurse Jeanne Avlastenok and Dr. Peter Østergren, have been working with the wives and partners of men who had been undergoing exercise therapy to maintain body strength and resilience during prostate cancer treatment. They questioned 56 women on how the cancers were affecting the lives of their husbands. Nearly half of these women (26 women, i.e. 46%) reported that their partner's health problem had affected their own health.

The researchers randomly selected 8 women for in-depth, focus-group style interviews – aimed at encouraging the women to express how they are being affected by their partner's illness.

"We worked with the women as a group, encouraging them to be open about what they felt in a supportive group environment", said Jeanne Avlastenok.

"Three of the women – those with early stage disease – were less burdened than the others, but the remaining five expressed some significant concerns.

Many felt increasingly socially isolated. Their husbands were fatigued both by the illness and by the treatment, which meant that they couldn't socialize as a couple, which made the women feel cut off from social support."

Sample Comment: "Because he sleeps so much we do not visit the family or our friends and do not have many guests" said one.

RN Jeanne Avlastenok continued, *"They also gradually developed a real fear of being alone, even within the relationship. They felt that they had to be strong, which meant that they couldn't share the burden of the illness.*

The last theme which worried the women was over the role change in their relationship. As their men became less able to fulfill their usual roles, the women had to undertake tasks which had previously fallen to the men. Many of these are simple tasks but for the women they represented a sea change in the way their lives were structured."

Sample Comment: 'We have 22 windows and my husband thinks that he still can polish them and also do all the gardening. But nothing happens and he doesn't want me to arrange professional help'"

All of the women were worried that their husbands would develop significant pain as the disease progressed.

The team stresses that the focus group findings is very much qualitative work on a small sample. *"But in any study, you need to do the qualitative work before moving to any larger sample"*, said Dr. Peter Østergren, *"We needed to let the women express their concerns first, so we can understand which questions to ask."*

Commenting, Professor Hein Van Poppel (Leuven, Belgium), EAU Adjunct Secretary General for Education, said:

"Many prostate cancer patients have a hard time, both physically and emotionally, and this work shows that this stress can spill over and affect wives and partners. This is good for neither of them. Good mental and emotional health needs to be part of how we judge a treatment, and we need to try to ensure that both patients and their partners get the support they both need".

Only departmental funds were used for this research.

ENDS

Notes for editors

PLEASE MENTION THE EUROPEAN ASSOCIATION OF UROLOGY CONGRESS IN ANY STORY RESULTING FROM THIS PRESS RELEASE

The 33rd European Association of Urology conference takes place in Copenhagen from 16th to 20th March. This is the largest and most important urology congress in Europe, with up to 14,000 expected to attend. Conference website <http://eau18.uroweb.org/>

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Abstract

Quality of life of spouses living with men undergoing androgen deprivation therapy for prostate cancer

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Introduction & Objectives Men with prostate cancer undergoing androgen deprivation therapy are offered a supervised group-based exercise program as standard of care at our department. One aim of the program is to improve the quality of life (QoL) of the patients. However, the QoL of the spouses are often neglected and we have previously shown that > 40% of the spouses report reduced QoL in a questionnaire survey. Thus, the objective of this study was to investigate factors that affect the spouses' experienced QoL and to investigate how Health professionals may help to reduce these burdens.

Materials & Methods Data was collected by a semi-structured focus group interview. Spouses from our previous questionnaire survey were randomly selected and invited to participate. The interview was audio recorded, transcribed, and analyzed using thematic analysis.

Result Eight spouses, all women, participated. Three key factors affecting the QoL of the spouses were identified.

- **Role change** The traditional marital roles changed as the man through his disease experienced fatigue and reduced energy, and thereby losing his ability to fill out the space and function, he usually had. The wives reported that the men were not entirely realistic in their own abilities and that they felt forced to take over, even with things they did not feel confident in. Furthermore, the men's priority of their resources did not match with the wishes of the wives (eg. continued training with other men from the structured training program instead of practical work at home).
- **Isolation** Some of the spouses reported that the fatigue of their husband limited social activities both outside and at home. This led to an experience of social isolation.
- **Alone and the fear of losing** The wives felt they had to not show vulnerability towards their husband or children, in order to appear as strong and caring people. However, they feared progression of their husbands' disease and his potential future suffering. This raised concerns of an uncertain future and the fear of losing. Many of the spouses felt alone with these feelings and experienced it was challenging to talk openly about this with their husbands and others.

Overall, the spouses found it difficult to pinpoint exactly which needs in their opinion, the health care professionals can address. However, they call for tools in form of written material informing about being a relative to a man with prostate cancer (eg. addressing how to deal with emotional issues, their own sadness and concerns, and what the expected course of the disease is, and how to prepare for losing a loved one).

Conclusions

In this study we found that the changing of marital roles, social isolation and the feeling of standing alone negatively influenced the experienced quality of life of spouses to men with prostate cancer. The spouses call for the Health care professionals to support tools that may help deal with these issues.

This work was presented on 18th March 2018