

# Androgen deprivation therapy for prostate cancer: Spouses' problems and needs for professional information and support

## **Research group**

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## **Title**

Androgen deprivation therapy for prostate cancer: Spouses' problems and needs for professional information and support.

## **Introduction**

Androgen deprivation therapy (ADT), commonly used for advanced prostate cancer, may cause various symptoms, both physical and mental, that affect both the patients' and spouses' quality of life. Men with advanced prostate cancer may live for a long period of time with their disease so the spouses are important caregivers and support persons to these men. The mean age of men diagnosed with prostate cancer in this is about 71 year; therefore the spouses are often old and fragile themselves. Studies show that ADT affects the couple's relationship but little is known about the specific needs of the spouses for information and support regarding the disease and its treatment.

According to the Patients' Rights Act, relatives are entitled to information and support regarding the patient's disease and condition. Moreover, in today's health care there is increased emphasis on patients staying at home as long as possible. This indicates that relatives are faced with taking care of patients that are sicker than before. It is therefore unacceptable that relatives do not receive adequate information and support to be able to fulfil these obligations. Currently there is no formal service that is specially aimed at supporting the spouses of men with prostate cancer in this country. Furthermore, information regarding the disease and its treatment aimed at spouses are scarce. Hence, it is important to assess what the main problems the spouses encounter and whether they need assistance with these problems in order to develop informational material and perhaps more concrete form of service.

## **Objectives and implications for practice**

The overall goal of the study is to assess spouses' problems and needs for information and support.

The results of this study will be used to:

- a) To develop informational material regarding advanced prostate cancer and its treatment based on spouses' needs for information
- b) To develop formal service for spouses aimed to meet their needs for support and information like e.g. support groups or interviews with a urological nurse.

### **Literature review**

The most common form of treatment for advanced prostate cancer is androgen-deprivation therapy (ADT), which can take the form of either surgical castration (orchiectomy) or chemical castration (with gonadotropin-releasing hormone [GnRH]). The American Society of Clinical Oncology recommends these agents as the initial treatment for patients with symptomatic metastatic prostate cancer and considers them to be of potential benefit in three other groups: patients with rising prostate-specific antigen (PSA) levels following surgery or radiotherapy, patients with node positive disease who are asymptomatic for metastases, and patients who are asymptomatic for metastases but have evidence of metastases on imaging studies (Loblaw *et al.*, 2007). Commonly recognized adverse effects include hot flashes, decreased libido, and erectile dysfunction, and patients are often warned of these three common side effects. However, there are numerous other potential complications. The impact of ADT on osteoporosis including risk of fracture has been well-described. More recently, ADT has been linked to worsening of co-morbidities including diabetes and cardiovascular disease, especially in those patients who had these underlying conditions prior to initiation of treatment. The prevalence of functional, cognitive, and physical impairments in an at-risk population of elderly prostate cancer patients undergoing treatment with ADT is not as well-documented but has been illustrated in recent research (Mohile *et al.*, 2009).

The nursing care of patients suffering from advanced cancer is not limited to the hospital setting but also occurs at home (Tsigaropoulos *et al.*, 2009). The support the patient receives from family, friends, and groups is very important in helping them cope (Ng *et al.*, 2006), but the wives are very often those who give the most support (Ng *et al.*, 2006). This cancer significantly affects the couples' daily lives, their dyadic and family relationships, and

their developmental stage (Harden *et al.*, 2006). The wives continuously monitor their husbands' well-being, and watch for signs of change in their partners. The disease demands a great adjustment as role reversal may take place as well as changes in intimate relationship of the couple as well as social interactions (Harden *et al.*, 2006). The hormonal treatment side-effects such as tiredness, sexual dysfunction and loss of intimacy may affect many aspects of the couple's relationship and cause physical and mental distancing in the couples relationship (Navon and Morag, 2003). The spouses also encounter problems such as the patients depression and altered personality (Tsigaropoulos *et.al.*, 2009). Moreover, urinary incontinence may have a greater adverse psychological effect on the partner than the patient (Couper *et al.*, 2006). Men and their spouses appear to have differing responses to the illness (Ezer *et al.*, 2006) and the spouses even seem to show greater psychological morbidity than their partners (Rees *et al.*, 2005). These spouses have wide-ranging informational needs (Echlin and Rees, 2002). However, their needs are often unmet due to lack of information and support (Echlin and Rees, 2002; Ezer *et. al.*, 2006; Adams *et al.*, 2009; Evertsten and Wolkenstein, 2010). To enable carers to cope with their distress and fulfil their supportive role, it is important to recognise and understand their experiences (Sinfield *et al.*, 2009; Tsigaropoulos *et al.*, 2009).

### **Relevance to urology nursing**

Urological nurses possess both extensive and specialized knowledge about the treatment and symptoms men on ADT experience. This knowledge can be of use to spouses of these men. By developing service that aims at improving the well-being of spouses of men on ADT the knowledge and experience of urological nurses is utilized for the benefit of both patients and their caregivers. This can also add to the knowledge base of urological nursing and hence expand their professional field of practice.

### **Methodology**

#### **Design**

The study employs a descriptive, exploratory cross sectional design. Data will be collected with a questionnaire that assesses the problems of spouses of men on ADT treatment and their need for support/assistance with these problems.

## Population and sample

The population of the study are spouses of men:

- that are presently on ADT treatment due to prostatic cancer
- have received treatment for a minimum of six months

The spouses:

- must be able to read and write the native language
- must be deemed by the study nurse to be mentally fluent enough to participate

The size of the population is not known since it is unclear how many men are being treated with ADT in this country. According to sales number of the ADT medications the estimated number of patients is somewhere around 200. The aim is to include 100 participants in the study.

## Procedure

Participants will be recruited through their husbands (patient) and through advertisement in news papers, cancer support groups or organisations for the elderly:

1. During a urological visit the patients will be given an introduction letter regarding the study and asked to deliver the letter to their spouses. If the patient accepts to do this, the urologists will collect information about the patients' names and phone numbers. The study nurse will collect the information at the urological office and contact the spouses by phone. If the spouse is interested in participating she will be (i) sent the questionnaire and a stamped envelope; (ii) visited at home if she prefers where the study nurse will assist with filling out the questionnaire; (iii) invited to come to meet the study nurse at the Institute for Nursing Science where she will fill out the questionnaire.
2. Advertisements will be placed in local and national newspapers, as well as in newsletters of cancer support groups and organisations for the elderly. The study nurse will also visit the support groups and organisations in order to recruit participants. A telephone number and a name of the study nurse will be in the ads.

Those who contact the study nurse will be offered the same method of answering the questionnaire as described above.

#### Instrument

Data will be collected with the questionnaire *Problems and Needs in Palliative Care*– caregiver form (PNPC-c). The PNPC-c is a checklist composed of 67 items designed to present a comprehensive picture of the problems experienced by caregivers and their perceived subsequent needs for care. For each item, caregivers are first asked to indicate if they find the issue to be a “problem” (Yes/Somewhat/No) and, second, whether they need professional attention/support for it (Yes, more/As much as until now/No). Caregivers also answer 16 questions concerning informational needs regarding treatment options, aids (e.g. elevated beds, wheelchairs etc.), nutrition, fatigue, intimacy, and social benefits to name a few.

The PNPC-c was developed by Osse *et al.* (2006) and is based on interviews with patients and their caregivers. The original questionnaire is in Dutch but has been translated into English with a forward-backward procedure. The reliability and validity of the Dutch questionnaire is acceptable (Osse *et al.*, 2006).

The version used here was translated from English. It was translated into this language and back by experienced cancer nurses who are fluent in both languages. The psychometric properties of this version have not been reported.

#### Statistics

Statistical analyses will be carried out by use of SPSS 16.00. Descriptive and parametrical or non-parametrical statistics will be used as appropriate. Significance level will be set at 0.05.

#### **Feasibility**

##### Timetable

Fall 2010 – Finalizing research proposal, questionnaires and seeking approval from ethical committee and acceptance from urologist to act as collaborators in the study.

January 1<sup>st</sup> – July 31<sup>st</sup> 2011: Data collection. Advertised in newspapers and journals, visits to organisations.

August through December 2011: Data entering, analysis and interpretation.

Presentation of data and write up for publication may extend into 2012.

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<b>Budget</b>		EUR
1	Research Nurse	7.000
2	Secretarial assistance	1000
3	Statistical assistance	1500
4	Translating and editing	1.000
5	Setting, posting and copying of questionnaier	650
6	Advertisements	1.000
7	Telephone	350
8	Driving	2.600
9	Travel expenses (conferences)	2500
	Budget:	17.600
	Overhead 6%	1056
	<b>Total budget:</b>	<b>18.656</b>

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Explanation:

1. Salary is based on the Nurses Association salaries
2. Estimated 40 hours @ 24,4 EUR an hour
3. Estimated 15 hours @ 100 EUR an hour
4. Based on experience of cost in translating and editing related to two journal articles
5. Based on actual cost i.e. Cost of paper, envelopes, postal cost etc.
6. Estimated cost based on cost of ads in local newspapers and speciality journals
7. A mobile phone is needed for all correspondences

Although the majority of participants live in the Metropolitan area participants will be from all over the country, not least from the largest town outside the metropolitan area, which is located 400 K from the capital.

It is estimated that the research nurse will drive 40 K on average for each participant

8. For presentation of findings. Estimated for two conferences
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The grant will be used to finance data collection. The researchers will apply for grants from The University Hospital, The Nurse's Association, The Cancer Association, and Scientific funds of Nurses' chapters for Urological Nursing and Cancer Nursing.

### **Ethics**

Approval will be sought to the National Bioethical Committee and reported to the country's Data Protection Authority as required by law. Participants' personal identification will never be used during data processing and no information will be taken from medical journals.

### **Conclusions/Relevance**

ADT causes various difficult symptoms that impede on the well-being of both patients and their spouses. The spouses are most often the patients' main caregivers and they are entitled to both information and support regarding the disease and treatment. Studies indicate that spouses experience great caregiver burden. Little is however known about their specific problems and needs for information or support and how these needs can be met. Urological nurses are in key position to assist these spouses because of their knowledge regarding the treatment and symptoms of prostate cancer. The study is the first conducted in this country that specifies the needs of spouses of men receiving ADT for advanced prostate cancer. The study will therefore provide vital information regarding the spouses' needs and may lead to improved service for this group.

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**Possible conflicts of interest**

The authors declare that they have nothing to disclose.