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Improving male patients coping with urinary incontinence after Prostatectomy
 Quantitative research project to identify prostate cancer patient’s information levels, expectations and current coping of urinary incontinence after prostatectomy - to improve nursery actions

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Introduction

Every year 4,400 new cases of prostate cancer are diagnosed in Denmark, which currently makes prostate cancer the largest cancer disease among men in Denmark. The number of patients who are diagnosed with prostate cancer has tripled within the last 15 years. (Kræftens Bekæmpelse, 2012).

Patients who are about to undergo a prostatectomy are offered information folders and pelvic floor exercises before the beginning of the operation. This is done as a result of that some patients are experiencing postoperative urinary incontinence up to 12 months after the surgical intervention. The information folders and pelvic floor exercises are offered at a time, where patients often are experiencing stressors triggered by the cancer-diagnosis combined with an operative intervention within the next 14 days.

The urethral catheter is removed postoperative 7-14 days after the surgical intervention and most patients will experience urinary incontinence in short or long periods. The patients can call the hospital and ask questions regarding problems, which they experience in relation to their urinary incontinence or other postoperative factors such as pain, sexuality or emotional aspects, in the period from the catheter removal to the subsequent 3 months of PSA-control.

As a nurse at the Urological Clinic of the University Hospital of Copenhagen, I have encountered that patients rarely call us with any emotional questions regarding their urinary incontinence which is also confirmed by my colleagues. When patients contact the Urological Clinic concerning their experiences of urinary incontinence, the questions are targeted towards practical reasons. Common questions are which diapers to use, how long they can expect the urinary incontinence to endure or which options they have to tackle their new problem with incontinence. The rational and practical approach to their questions, when contacting the Urological Clinic regarding urinary incontinence over telephone, is a contrast to my personal observations when dealing with the patients' experiences and emotional embarrassments. It is evident that the lack of control of their urinary behaviors challenges their perception and respect for themselves more than they reveal at first hand. A rising number of patients express a decrease in social interactions and quality of life. They report a constant feeling of insecurity because of their urinary incontinence, when entering

public domains such as restaurants, cinemas or when using public transportation, in fear of sudden obnoxious smells activated by their incontinence. As a result they would rather stay home and avoid social gatherings, which leads to isolation.

It is my observation that urinary incontinence is more prominent than the first impression based on the number of approaches over the telephone. This observation is confirmed by a research (Wellam & Sawatzky, 2008), which shows that more than 50 % of the patients who received a prostatectomy, experience urinary incontinence. The consequence is a decrease in quality of life caused by the embarrassment that comes with the lack of control of their urinary incontinence. Another analysis (Palmer, 2003) reveals that patients' quality of life is decreased in 3 areas. Patients experienced an emotional unstableness caused by their decrease in body control, which led to embarrassment, shyness and depression. Another area was a reduction in their social life. Patients avoided restaurants, bars, cinemas, gyms, family gatherings and weddings, which had a significant importance for their experienced quality of life. The last area was the physical, where urinary incontinence started a reaction of skin eruption, itching and other physical discomforts. The physical discomforts were the least significant problem in comparison to the decrease in quality of life caused by urinary incontinence.

Summary

It is my perception and experience, that there is a significant difference between the reason for patients with urinary incontinence to call the hospital in contrary to the impact the surgical intervention has on patients through social, physical and emotional challenges.

My experience has been confirmed in the literature and international researches. These differences have given me a desire to conduct a survey with the purpose to understand which information and expectations the Danish patients have in relation to urinary incontinence after a prostatectomy and furthermore to understand how they deal with the difficulties of urinary incontinence.

Objectives

The main objective with the research paper is to identify patient's level of information and expectations to urinary incontinence after a prostatectomy and understand how patients deal

with their incontinence today. The result of the research will be used to improve nursery action in order to help the patients coping with urinary incontinence after a prostatectomy.

This research paper is important to conduct whereas the number of Danish patients diagnosed with prostate cancer will increase and therefore an increased demand for urological nurses to optimize the information given to patients.

Literature Review

I started seeking information in International Databases (PubMed and Cinahl) about urinary incontinence with key words: *Male patients, Coping, Urinary incontinence and Prostatectomy in the period after year 2000*. The search resulted in 42 international articles or surveys, primarily based on studies in the US or UK. There were no surveys done in Denmark. All the International surveys were centered on the subject with different approaches and across the surveys, two overall problems occur, which decreases the patients coping with urinary incontinence and which can lead to a reduced quality of life and an increase in depression.

The first problem is anchored in the feeling of a lack of control over the body's functions. The circumstance that patients cannot control their secretion of urine gave them significant emotional challenges (Palmer, 2003). They felt shame and unworthiness and therefore preferred social isolation in comparison to putting themselves in difficult situations where they in public could risk a mental humiliation.

Urinary incontinence after a prostatectomy is a subject to taboo because in the modern western society we attach a negative significance to the lack of control of our body's secretion. The society sees it as a shameful and humiliating thing. (Jocalyn Lawler, 1996) Another factum, which increases the shamefulness of patients, is that the public debate concerning urinary incontinence of men is almost non-existent. The consequence of the minimal attention in the public debate gives urinary incontinence patients a feeling that the problems only occur in their case. Therefore they avoid support groups unless nurses actively offer them. One of the analyses (Cynthia M. Sublett, 2009) used a VAS-score with a scale from 1 to 10, where patients were asked to point out their level of embarrassment in different situations, which were displayed on different pictures: a stain on trousers, obnoxious smells etc. The conclusion was that men with urinary incontinence

needed assistance in order to successfully cope with the embarrassment regardless of the level of embarrassment. Even those with a low level of embarrassment showed a need for professional assistance.

The shame and feeling of unworthiness that comes with the lack of body control led to a certain degree of isolation in all researches. Many men preferred the isolation to the embarrassment and shame that might occur when contained in public areas. The isolation does not only affect the husband when he prevents himself from taking place in traditional activities such as restaurants, movies and dinner parties. The isolation affects the wife likewise because it also isolates herself from these activities. In a qualitative analysis (Maliski, 2001) conducted among 10 couples where the man had urinary incontinence and a control group of 10 couples without urinary incontinence after a prostatectomy, stated clearly that the wife's way of dealing with the incontinence had a significant importance. All couples were in agreement that the single most important thing was to get rid of the cancer. The removal of the catheter was regarded as a part of the rehabilitation among the men, but none of them could handle the following urinary incontinence. The cohabiting partner handled in most cases the man's and their own fear, but also assisted with practical coping of incontinence to limit the difficult situations.

The partner often functioned as a catalyst in the rehabilitation process but also as a connecting link between nurse and patient. An emotional and practical support to improvement of the patients coping with urinal incontinence was an important factor when avoiding the possible isolation of the patient and his partner. The cohabiting partner is evidently an important factor in the treatment of the patient in order to improve the patients coping with urinal incontinence after a prostatectomy.

Relevance to urology nursing

As it appears from the above international research, that patients find it difficult to cope with the important consequences involving urinary incontinence after a prostatectomy. The number of patients diagnosed with incontinence after a prostatectomy will gradually increase in the future. As a result there is a higher demand for urology nurses to optimize the information pre-operative, to meet the expectations and to advise action plans, which ensures improved coping of urinary incontinence after a prostatectomy. A specific study among Danish patients will give us the

necessary insight to improve the nurses and the interdisciplinary effort to ensure a better coping for the patients with incontinence after a prostatectomy. Today we do not have these insights on the Danish patient's ability to cope with urinary incontinence.

Methodology

The research study will be conducted as a Cross-sectional survey in the same format as the survey conducted by Palmer in 2003 among American patients. The Cross-sectional survey has the advantage of being able to estimate prevalence of urinary incontinence after prostatectomy and to identify the problems associated with the coping. It also gives us the opportunity to decode data and take a thoroughly look at different age groups and different courses. The disadvantage of the Cross-sectional survey is that it is only a snap-shot of the current situation. Different results may occur if another timeframe had been chosen.

The survey will be conducted through a combination of multiple and open questions. The questionnaire will be developed by best practice from international surveys and supplied with knowledge from a group of experts consisting of: Urology nurses, doctors and organizations (PROPA). After finishing the questionnaire it will be sent to patients who have given an informed consent and meet the following inclusion criteria:

Inclusion

Patients who have received prostatectomy and experienced urinary incontinence in connection to the surgical intervention, within the last year or earlier.

Exclusion

Patients who have experienced urinary incontinence before the surgical intervention and patients who have not experienced urinal incontinence after the surgical intervention will be excluded in the analysis.

The questionnaire will be sent by PROPA. PROPA (Prostate Cancer Union) is an independent organization that co-operates with Kræftens Bekæmpelse. In the research study I want to send out invitations to the PROPA members to attend the research project. This method was used by (Palmer, 2003) and gave a 45 percent of recruitment. The recruitment was also conducted through

their website. The recruitment method will give the research study reliability and simultaneously a nationwide character, which is important in order to gain high relevance in Denmark.

The objective is to get at least 100 Danish patients to participate. The target seems to be realistic because 1,000 prostatectomies are performed each year and with a recruitment percent of 45, this will roughly give more than 450 patients to recruit from. Survey data will be processed through SPSS (Statistical Software Package) from an extern collaborator and the open questions will be grouped and commented on. All patients will be anonymous in the survey and only the key result will be published in relevant Urological Journals like EUT: European Urology Today.

Feasibility

The project will start in April 2015, where a dialogue with PROPA will be intensified. The questionnaire will hereafter be established in collaboration with PROPA, urology nurses, doctors and organizations. Mails and invitations to the patients will be mailed in July 2015.

Best practice from similar tests indicates a 5 months period of sampling to secure at least 100 replies. An extern collaborator will perform the data processing through SPSS where the results will be reviewed from February-March 2016. Conclusions and abstracts will hereafter be conducted, which will function as a starting point for implementing the results to practical procedures performed by nurses. The estimated time for the project is expected to be 1 year and 3 months.

	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
2015:												
Dialogue with PROPA				X								
Questionnaire					X	X						
Mail to PROPA members							X					
Sampling								X	X	X	X	X
2016:												
SPSS handling	X											
Reporting		X	X									X
Conclusion				X								
Abstract					X							
Implementation of findings						X	X	X				

Throughout the project a demand for funding is needed in order to establish and publicize the questionnaire but also to perform the data processing from an external source through SPSS. Funds will be applied for from EAUN, PROPA and the Nurse's organization.

Conclusion

Urinary incontinence is a frequent problem after receiving a prostatectomy and it has a significant negative role in the patients' perception of quality in life. Correct and punctual information, concrete steps and guidance are vital aspects in nursing action to minimize the problems that occur when experiencing urinary incontinence. Today we are in need of sufficient and structured knowledge about Danish patients' experiences with urinary incontinence. The lack of knowledge is an important issue to maximize the patient's coping with urinary incontinence after receiving a prostatectomy. Another reason for conducting this survey is the fact that the number of patients with prostate cancer is increasing and hereby accelerating the problem. This is the reason for my wish to conduct this research survey in order to find out how nurse- and interdisciplinary actions can be improved, which will improve patients' coping with urinary incontinence after a prostatectomy.

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Conflicts of interest

None.