

# Needs and expectations of patients with prostate cancer and their partners

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## Development of an innovative and comprehensive nurse consulting in Switzerland

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## 1. Introduction

Prostate cancer (PC) is the most frequent cancer and is with 14.9% the third leading cause of cancer death in men in Switzerland. The incidence rate of PC is 29% of all cancers, with 5650 cases per year in Switzerland (American, 2011; Boyle & Ferlay, 2005; Haas, Delongchamps, Brawley, Wang, & de la Roza, 2008; Jemal et al., 2008; NICER, 2011, 2013). Depending on the stage of disease (PCP) have different options of treatment: Active surveillance, prostatectomy, hormonal therapy, chemotherapy and radiotherapy. The patients are confronted with a life threatening cancer diagnosis, will experience emotional burden and side effects from the chosen treatment. Depending on medical therapy, PCP may suffer from: erectile dysfunction and incontinence due to prostatectomy; fatigue, hot flushes and taste disorders due to chemotherapy and radiotherapy; adiposity and sleep disorder due to hormonal therapy; urine flow disorder and pain during active surveillance. These side effects can lead to depression, distress and uncertainty (Eton, Lepore, & Helgeson, 2005; Hagedoom, 2008). Depending on the stage of the disease PCP may experience pain as a consequence of bone metastasis. This symptom is prominent at the palliative stage too. It is well known that partners of PCP are burdened and feel disempowered by the cancer diagnosis and the following treatment too. They would feel better, less anxious and more confident when caring for the PCP if they were adequately informed and supported with issues related to side effects and treatment (Feltwell & Rees, 2004).

Based on these facts there is obviously a high need for professional support and counseling for PCP and their partners. This can be done by systematic program offered by an Advanced Practice Nurse (APN). The program should start at the moment of diagnosing prostate cancer and continue according to the needs of the patient and his partner over the whole period of the disease, until end of life (Cockle-Hearne et al., 2013). Patients and their partners will thus benefit from long-term nurse consulting.

These findings inspired us to develop a nursing concept with a special program for PCP and their partners led by an APN. We will introduce this consulting service in 2014.

To adapt APN consulting optimally to patients` and partners` needs, the purpose of this study is:

- 1) a) to explore experiences of PCP with illness and related therapies, symptoms and side effects,  
b) to explore experiences and further expectations of PCP with APN consulting.
- 2) to optimize the APN consulting according to patients` needs based on the results of the qualitative study.
- 3) to describe the number of consulted patients and partners, their demographic and clinical characteristics, the number, duration and content of consultations.

Later, a second study will be developed to evaluate the APN consulting intervention quantitatively.

## 3. Literature Review

A literature review was done in the year 2012. The purpose of the review was to give an overview in relation to empowerment patient education programs for PCP. The concept of 'empowerment' plays an increasingly important role in the care of patients and is a significant instrument in consulting PCP. Rappaport describes the origins of the concept in 1980. The focus lays on "psychology and community empowerment" (Rappaport, 1987). Spring (1997 p. 2-3) states that empowerment is similar to a process with which different personal resources will be promoted. These could be for example: „[...] having power for decision-making, having access to information and resources, having a range of options to make choices, assertiveness, a feeling that the individual can make a difference (being hopeful), learning to think critically, learning about and expressing anger, not feeling alone, feeling part of a group, understanding that people have rights, effecting change in one's life and one's community, learning skills (e.g., communication) that the individual defines as important, changing others' perceptions of one's competency and capacity to act, coming out of the closet, growth and change that is never ending and self-initiated, increasing one's positive self-image and overcoming stigma" (Spring, 1997). These facts and the previous described gap are the basis for our idea to initiate an APN consulting for PCP.

Six studies were included after a search in the databases Pubmed and Cochrane Library, with the search words:

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empowerment, patient empowerment, education, decision making, randomized controlled trial and prostate cancer. The words were used as MESH-Terms or free words in different combinations with the words "AND/ OR". A search strategy with inclusion and exclusion criteria was defined. Inclusion criteria were: the abstract and full text was available, publication was in English or German, patient's diagnoses is PC or patients are interested in precaution. Publications in the period from 2000 to 2012 were enclosed. Excluded were qualitative studies and when studies were not empirical, like for example study reports.

The selection of the studies occurred at first through the suitable title. Secondly, the abstract was sighted whether the contents of the studies was appropriate or not. In a third step, the full texts were read and appraised for contents, design, results and evidence level. The orientation of the studies' evidence occurred with the help of the overview "Oxford Centre for Evidence - based Medicine - Levels of Evidence" (Oxford Centre for Evidence-based Medicine, 2009). The critical analysis was done by an APN. In the following part, a short overview of the consulting interventions will be given.

Participants of the study of Chan, et al. (2010) got information scripts and slides with video clips. A short booklet called "Men guide", which presents the same information of the scripts and video clips was given to the participants. Objectives of learning were 1) health-related decision making about screening needs, 2) find a role in decision making, 3) involved in a decision making process of prostate cancer screening, 4) consultation with others, 5) discussion with health providers about screening decision, 6) decision is based on information and characteristics of the test and personal preferences, and 7) effects of their decision. Results show differences between the intervention group and the control group. The intervention group shows a knowledge increase after the program ( $b=3.83$ , S.E. = .54,  $p < .001$ ), as well as a higher motivation to take part in secondary prevention, like PSA – test ( $p=.001$ ), 23% vs. 3% (Chan et al., 2011).

Another focus on empowerment programs is given in the RCT of Mishel, et al. (2002). Patients with prostate cancer were examined after surgical treatment or in the first three weeks after radiation therapy. In this case nurses supported patients with phone calls. The participants with two different ethnicities, African-American & Caucasian, were split in three groups, 1) direct uncertainty management, 2) supplemented uncertainty management and 3) usual care group. The direct uncertainty management intervention is described in two steps. In the first step, a trained nurse conducted weekly phone calls during eight weeks and assessed patient's needs by a semi-structured interview. In the second step, the nurse informed the patient about interactive resources and supported him to understand symptoms due to treatment. Participants learned also how to ask questions during consultations with their medical doctors. Written information was also handed out. Participants got emails with written material, audiotapes and videotapes after each weekly telephone call. In comparison to the direct uncertainty management intervention, participants of the supplemented intervention got additional help for their family support person. This person got weekly phone calls for eight weeks. The results show significant differences over time by treatment group 1) for cognitive reframing ( $p=0.005$ ), and group 2) from baseline to 4 months ( $p=0.009$ ). The control group had improved in cognitive reframing by regaining their initial loss from baseline to 7 months ( $P=0.002$ ). Patients in treatment groups showed better problem solving as those in the control group ( $p=0.049$ ). A decrease in the number of symptoms over time for all groups was present ( $P=0.001$ ). And a significant decrease over time in all groups for reported intensity of symptoms was proven ( $P=0.001$ ) (Mishel et al., 2002).

Other outcomes like increased knowledge, satisfaction and decreased decisional conflict were presented in the RCT of Taylor, et al. (2006). The aim of the study was to proof a screening education program for African American Patients. After a completion of a baseline interview, participants were randomly assigned to one of the 3 interventions a) video-based information, b) print-based information, and c) wait list control. Participants of group a) got a 25-minute videotape. On this tape an African American presents his story, how to make a decision on prostate cancer screening. Information about the disease was presented and a discussion took place between the African American and friends and family members about the pros and cons of screening and the fear experienced. At the same time, a medical doctor showed diagrams of prostate cancer and screening. A celebrity, like "Frank Robison" is also included on the videotape to give information. In group b) participants got a 16-page printed guide. This guide includes information about prostate cancer, symptoms, anatomy, function, risk factors, benefits and limitations of screening, possible question to ask and a glossary of terms. Information from a celebrity " Frank Robison" and a prostate cancer survivor are presented. The analysis of the data in this study, show a higher knowledge in print group and video group after 1-month assessment ( $P<0.0001$ ). In the first follow up increasing

knowledge was higher in print group vs. video group after 1-month ( $P < 0.0001$ ). With the view of decisional conflict decreased direction from baseline to 1-month assessment only in print group ( $P < 0.0001$ ) is described. Print intervention resulted in significantly reduced decisional conflict vs. video intervention (OR, 0.21; 95% CI, 0.09-0.52). Yet, the satisfaction of participants with screening decision was not related to the intervention arm (OR, 0.64; 95% CI, 0.28-1.4). However, after one year follow up, there is no sig. association between intervention groups and having precaution, but marginally significant association between lower decisional conflict at baseline and having undergone screening at 1 year ( $P = 0.056$ ) is specified (Taylor et al., 2006).

The Cochrane review of Stacey, et al. (2012) is more detailed in the presentation of patient outcome. In total 86 intervention studies were included in this review to present the effects of decisional support programs for patients screening prostate cancer. Main results of the review are on the one hand: increasing knowledge by decision aid (MD 13.77 out of 100; 95% CI 11.40 to 16.15;  $n = 26$ ); lower decisional conflict (MD -6.43 of 100; 95% CI -9.16 to -3.70;  $n = 17$ ); reduce proportion of people who were passive in decision making (RR 0.61; 95% CI -7.23 to -2.40;  $n = 14$ ); and appear to have positive effect on patient-practitioner communication. On the other hand, satisfaction of the participants with decision aids or process, exposed to be more satisfied.

In summary, it turns out that the combination of education methods is important for different learning types. The increase of knowledge and the promotion of safety during the decision-making process can be defined as a positive outcome. It is also shown that nursing consultation can reduce the number of experienced symptoms in PCP. It becomes clear that none of the EPE programs were using an APN for the consulting.

#### 4. Advanced Practice Nurse Consulting

An Advanced Practice Nurse (APN) has a Master degree or PhD, she is experienced in clinical practice on advanced level with focus on patients and their families in a specialized field. Advanced Nursing Practice (ANP) is defined as specialized nursing practice and serves as the collective term of various professional designations like Advanced Practice Nurse (APN), Nurse Practitioner (NP), Nurse Anesthetist (NA).

The APN in our new consulting service is a nurse with a Master of Science in Nursing, specialized in urology oncology nursing. We will develop her role according to the model of Hamric, et al. (2009). She provides direct care and consulting to PCP and their partners. The main focus will lie on supporting and empowering patients in knowledge about PC, in decision making, in coping with illness and in symptom management. Every PCP will have the option to take part in the consulting service either personal face to face at the outpatient clinic and when he is hospitalized or by telephone call, if he stays at home. The following topics will be covered in the consultation:

- Health promotion (nutrition, sports, social life)
- Information about cancer risks (public events)
- Coordination of and information about examinations (CT, MRI, etc.)
- Emotional and psychosocial support (isolation, stress, anxiety, uncertainty, depression)
- Prepare and explain patient and partner for medical consultation and examination
- Transfer of knowledge about disease, therapy and symptoms
- Coping with diagnose and side effects
- Support in symptom management and handle symptoms in everyday life (work, hobbies)
- Coordination and support of contact with external / internal partners (Psycho-oncology, Social Services, Cancer League Switzerland, self-help groups)
- Assistance in obtaining equipment (incontinence, erectile dysfunction)
- Support in the end of life stage

#### 5. Relevance to Urology Nursing

In this study, the APN accompanies the patient and his partners during the whole process of disease and treatment. This means the APN is counseling and educating patients in the inpatient and outpatient setting and in domestic area. An increase in quality of life and knowledge as well as a reduction of distress for patients and their partners are expected. Additionally the APN will promote knowledge in oncology among their nursing colleagues. Patients' needs and potential problems will be detected earlier through case discussions. This enables the inclusion of interdisciplinary services, such as psycho-oncology and social services earlier. Furthermore, the APN

will professionalize oncological care in the Urology Department. This in turn has a positive effect on the recovery of the patient and his partner.

The APN – support is internationally in progress. Different approaches have already been integrated into the care of PCP (Cockle-Hearne et al., 2013). The initiation of an APN – support in the care of PCP and their partners from the initial diagnosis through to end-of-life stage has not yet been published internationally nor in Switzerland. In summary, there are no publications about APN consulting for PCP and their partners, who get support from their precaution until the end-of life stage. With this project, there is the aim to generate new facts.

## 6. Methodology

A qualitative study will be performed to illustrate the experiences, needs and expectations of PCP. Telephone interviews and focus-group interviews are planned. The aim of the qualitative study is to integrate the results into the consultation pathway, as an optimization of the APN – consulting concept.

A quantitative evaluation of the APN consulting will be planned after the qualitative study. A pre-post design with patient outcomes like self-efficacy, distress and knowledge is the aim of the second step.

### 6.1 Objectives

The present study will give an overview about the situation of PCP, how they experience their disease and the consultation of an APN. Thus, the research questions are as follows:

- a. How do patients with prostate cancer experience their disease?
- b. How do patients with prostate cancer experience the consultation service of an APN and what are their expectations?

### 6.2 Setting und Sample

The study will be conducted on a Urology Department at an University Hospital in Switzerland. All patients with PC who will be treated by Prostatectomy, Chemotherapy, or Radiation therapy will be included. Consecutively, 30 patients will be recruited, 10 per treatment group, for single interviews. In addition, 3 groups of 5 to 7 patients will be recruited, one group per treatment, for focus group interviews. Different stages of PC are allowed to participate in the study. There is no age restriction. The patients should take part in a minimum of 2 consultation sessions with the APN. Access to and recruitment of patients with PC is based on the tumor board and the diagnostic announcement with treatment recommendations. The recruitment of PCP will take between 2 and 4 months.

### 6.3 Data Collection

Using an interview guide, semi-structured interviews with open-ended questions will be conducted. Themes of the interview guide are: 1) experiences of the disease and diagnosis; 2) hospital stay; 3) received information by the APN; 4) expectations of the APN consulting and 5) about the time of APN consulting. This methodological combination allows a deeper exploration into the experiences of PCP.

On the one hand, open-ended questions make it possible for the patients to name all important points of their life with PC. A problem with this method is that the willingness of the interviewee to discuss all topics, this could result in a time consuming process. On the other hand, semi-structured interviews focus on a theme, that helps to restrict the conversation to the salient points or experiences. This is important for telephone calls, because of time constraints and personal resources.

The telephone interviews will be conducted by a nurse 3 months following the treatment. The nurse is not involved in the consultation of PCP. About 20-30 minutes for a telephone interview and 45-60 minutes for a focus group interview will be planned. The interviews will be recorded by audio tape, transcribed and afterwards analyzed.

### 6.4 Data Analysis

For data analysis, the content analysis by Mayring (2008) will be used for telephone interviews (Mayring, 2008). For the focus group interviews concept mapping will be taken (Nesbit, 2006). The telephone interviews are used for data basis. Findings of the telephone interviews will be presented to the focus groups and the participants will be

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asked to comment and expand on these themes, to add any additional issues or concerns. Combined, all these methods help to capture the views and experiences of PCP more accurately.

### 6.5 Ethical consideration

Three months after treatment the patient will be asked by telephone call or in person whether he would be interested in participating in a telephone interview or focus group interview. If the answer is yes, the patient will receive information about the qualitative study. All participants will provide a written informed consent. The collected data will be anonymous. It will be possible for the patient to leave the study group at any time upon request. This decision will not impact future nursing care or support. All patients, whether incorporated or not, receive the same care and support from the APN.

### 6.6 Quantitative future study

After the qualitative analysis and the implementation of the results in the consultation pathway, a quantitative evaluation of the ANP consulting is planned in the future. A pre-post design with patient outcomes like self-efficacy, distress and knowledge is the aim of the second step.

## 7. Feasibility

### 7.1 Time table qualitative part 2014 – 2015

	2014			2015					
	May- June	July- Aug.	Sep.- Oct.	Nov.- Dec.	Jan.- Feb.	March- April	May- June	July- Aug.	Sep.- Oct.
<b>1. Approval of ethics committee</b>									
<b>2. Patient recruitment</b>									
<b>3. Data collection</b>									
<b>4. Data analyses</b>									
<b>5. Results &amp; Conclusion</b>									
<b>6. Dissemination</b>									
<b>7. Theory-Practice Transfer</b>									

### 7.2. Budget

Personal tasks and resources	hours	Costs CHF	Costs €
Ethics committee		500	410
Data collection	51 h / a 27,50 CHF	1410	1150
Qualitative data of 33 interviews: transcription and analyses	114 h/ a 27,50 CHF	31340	2550
Dissemination of results: Publication	30 h/ a 27.50 CHF	830	680
<b>Total costs in €</b>			<b>4790</b>

## 8. Conclusion

In summary, the findings of this qualitative study will 1) improve the understanding of PCP experiences regarding illness, therapies, symptoms and side effects; 2) give insight into patients` experiences, who take part in APN consulting. Subsequently, the APN consulting will be adapted. In addition, this first study will provide the basis for planning the second step, that is a quantitative evaluation of the APN consulting intervention. The project of an APN consulting for PCP and their partners helps to optimise the patient care on an evidence-based level.

## 9. Conflict of interest

None of the authors has a conflict of interest to declare.

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